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ABSTRACT

The report describes the first national conference on temporary family supports and integrated respite services systems for the developmentally disabled held in 1978. Program planning information is presented along with evaluation feedback summarized from participant responses. Recommendations from the conference are discussed, including development of a national and state level communication network, provision of consumer education regarding the rights of handicapped persons, and introduction of new federal and state legislation. Conference attendees are listed. The bulk of the document is composed of appendixes, including descriptions of 12 support services, the sample survey form, and a list of publications and resources. (CL)

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FINAL REPORT OF THE FIRST NATIONAL CONFERENCE ON TEMPORARY FAMILY SUPPORTS FOR DEVELOPMENTALLY DISABLED PERSONS

MAY 3-5, 1978

HOLIDAY INN

BETHESDA, MARYLAND

PRINCIPAL AUTHORS AND EDITORS

TAWARA D. TAYLOR

AND

BERTINE LOOP

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MEYERS CHILDREN'S REHABILITATION INSTITUTE
UNIVERSITY OF NEBRASKA MEDICAL CENTER
OMAHA, NEBRASKA

EC131705

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PRELIMINARY CONFERENCE PLANS

THROUGH CORRESPONDENCE, PHONE CALLS, AND A SUBSEQUENT TWO-DAY MEETING IN BOSTON, MASSACHUSETTS, CONTACT WAS MADE BY GEORGETOWN UNIVERSITY CHILD DEVELOPMENT CENTER WITH MS. BERTINE LOOP, OF THE CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS (CASS). THE CENTER IS HOUSED AT THE UNIVERSITY OF NEBRASKA MEDICAL CENTER AND SPONSORED BY THE MEYERS CHILDREN'S REHABILITATION INSTITUTE (UAP). THE RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT, WHICH MS. LOOP COORDINATES, WAS AWARDED A NATIONAL SIGNIFICANCE GRANT BY THE DEVELOPMENTAL DISABILITIES ADIVSORY COUNCIL IN 1976 FOR TWO YEARS. THE CASS PROJECT HAS BEEN INVOLVED IN IDENTIFYING AND DEVELOPING COMMUNITY-BASED TEMPORARY FAMILY SUPPORT SYSTEMS THROUGHOUT THE COUNTRY.

THE CASS PROJECT STAFF PERFORMS SITE VISITS, TRAINING AND TECHNICAL ASSISTANCE TO PROGRAMS ACROSS THE COUNTRY. CONSUMER ORGANIZATIONS, DD COUNCILS AND OTHER NATIONAL, REGIONAL, STATE, AND LOCAL GROUPS WERE ASKED TO IDENTIFY AND REFER PROGRAMS TO THE CASS PROJECT. CASS COMPILED AN EXTENSIVE RESOURCE LIST MADE UP OF ORGANIZATIONS, GROUPS, AND COMMUNITY SERVICE PROGRAMS. THE PROJECT IS FINALIZING "HOW-TO" RESOURCE MATERIALS DESIGNED FOR USE BY DD COUNCILS, CONSUMER GROUPS, AND OTHER COMMUNITY-BASED PROGRAMS. CASS' EXPERTISE COUPLED WITH GEORGETOWN'S NEED TO ORGANIZE A CONFERENCE AND DEVISE A COMMUNICATION NETWORK LED BOTH PROGRAMS TO DISCUSS JOINT SPONSORSHIP OF A NATIONAL CONFERENCE.

A NATIONAL CONFERENCE ON RESPITE CARE AND TEMPORARY FAMILY SUPPORT SYSTEMS HAD NEVER BEEN ATTEMPTED BEFORE. GEORGETOWN PROPOSED THE IDEA TO THE DEVELOPMENTAL DISABILITIES OFFICE, DHEW REGION III FOR APPROVAL. CASS OBTAINED APPROVAL AND INPUT FROM THE NATIONAL DEVELOPMENTAL DISABILITIES OFFICE. THE JOINT VENTURE WAS APPROVED AND PREPARATIONS BEGAN TO TAKE PLACE BY MID-FEBRUARY, 1978.

THIS WOULD BE THE FIRST NATIONAL CONFERENCE WHICH WOULD EXCLUSIVELY FOCUS ON THE DEVELOPMENT OF TEMPORARY FAMILY SUPPORTS AND INTEGRATED RESPITE SERVICES FROM THE PERSPECTIVE OF THE TOTAL COMMUNITIES.

REASON FOR THE CONFERENCE

BOTH CASS AND GEORGETOWN FELT STRONGLY THAT TEMPORARY FAMILY SUPPORT SERVICES, AND COMMUNITY-BASED PARTICULARLY RESPITE SYSTEMS HAD BEEN A LARGELY NEGLECTED AREA. THERE WERE MANY ISSUES AND CONCERNS RAISED IN GEORGETOWN'S INITIAL PROGRAM SURVEY AND THROUGH CASS' WORK THAT COULD BE MORE ADEQUATELY ADDRESSED IN A NATIONAL ARENA.

HISTORICALLY, TEMPORARY FAMILY SUPPORT AND RESPITE SERVICES HAVE BEEN LIMITED TO INFORMAL, IN-HOME SERVICES (E.G. SITTER SERVICES) OR OUT-OF-HOME SERVICES (E.G. DESIGNATED BEDS, INSTITUTIONS, HOSPITALS). THE DATA COLLECTED BY CASS INDICATED AN EMERGING TREND OF DEVELOPMENT AND LIMITED PROGRAM EXPANSIONS TO INCLUDE A BROADER RANGE OF SHORT-TERM SERVICES TO SUPPORT FAMILIES WITH DEVELOPMENTALLY DISABLED MEMBERS.

IDEALLY, THESE PROGRAMS WERE DESIGNED TO BE HIGHLY INDIVIDUALIZED AND RESPONSIVE TO THE NEEDS OF CONSUMERS AND THEIR FAMILIES. IN REALITY, THE RESPITE PROGRAMS DEVELOPING WERE CONTINUING TO BE SEGREGATED, FRAGMENTED, UNDERFUNDED AND WITHOUT COMMUNITY AGENCY SUPPORT, LEGISLATIVE MANDATE, OR ADEQUATE CONSUMER INVOLVEMENT FOR APPROPRIATE PLANNING AND IMPLEMENTATION. FINALLY, PROGRAMS WERE OPERATING IN ISOLATION WITHOUT COMMUNICATION AND LINKAGE TO OTHER SIMILAR PROGRAMS TO EXCHANGE RESOURCES, PLANNING TECHNIQUES, OR OPERATIONAL PROCEDURES.

DURING THE TWO YEARS OF THE NATIONAL RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT, CASS HAD IDENTIFIED EIGHT COMPONENTS OF A MODEL COMMUNITY-BASED SYSTEM OF TEMPORARY FAMILY SUPPORTS AND RESPITE SERVICES. THESE COMPONENTS CAN BE DESCRIBED AS FOLLOWS:

*1) CONSUMER PROGRAMS - ADVISORY COMMITTEES; MONITORING TEAMS; PARENT SUPPORT GROUPS; PERSONAL SELF-ADVOCACY.

*2) LEGAL FRAMEWORK - INSURANCE AND ADMINISTRATIVE PROCEDURES; REGULATORY MECHANISMS; STANDARDS AND MONITORING PROGRAMS.

*3) GENERIC AGENCY DEVELOPMENT - COMMUNITY ORIENTATION AND EDUCATION.

*4) Training - Parent training in specific intervention skills and monitoring of service delivery.
- Personnel preparation: orientation; inservice; and specialized skill training.

5) In-Home services - Homemaker/Home Health Aides, county-cooperative extension services, visiting nurse associations, sitter and companion services.

6) Out-of-home residential programs - temporary foster care; core residential facility and reserved bed programs.

7) Temporary day care - (includes out-of-home companion and sitter services) and family day-care homes; drop-in centers; integrated pre-schools and day-care centers.

8) Family resource services - includes information and referral services; parent cooperatives; family crisis and hotline services; counseling supports; recreation; equipment; transportation; employment; education; toybraries and resource libraries.

The first four of these components (*) are the cornerstones upon which the other four major components of service delivery development are dependent. Unless a respite services program includes these crucial components (legislative and funding development, generic agency development, consumer programs, and training), the service program will not likely survive the perennial funding issues or resolve its programmatic limitation and problems.

A National Conference was viewed as an excellent vehicle for communication between programs, lobbying for federal administration awareness and support, and working toward solving many of the problems of stable funding, legislation and consumer involvement.

FINAL CONFERENCE PLANS

SOLICITING FINANCIAL SUPPORT FROM STATE DD COUNCILS AND LOCAL ASSOCIATIONS TO SPONSOR REPRESENTATIVES TO SPEAK AT THE CONFERENCE WAS ASSUMED BY CASS. GEORGETOWN BEGAN WITH THE PRELIMINARY TASKS OF LOCATING SPATIAL ACCOMMODATIONS. GEORGETOWN ALSO RECRUITED ADMINISTRATORS OF VARIOUS FEDERAL GOVERNMENT AGENCIES THAT SUPPORT OR FUND SERVICES FOR THE HANDICAPPED, TO BE CONFERENCE SPEAKERS AND PANELISTS.

OVER TWO THOUSAND PRELIMINARY FLYERS WERE MAILED OUT ON MARCH 14, 1978, ANNOUNCING THE DATE AND PLACE OF THE CONFERENCE (SEE ATTACHMENT). THE CONFERENCE WAS SCHEDULED TO BE HELD MAY 3, 4, AND 5 AT THE HOLIDAY INN, BETHESDA, MARYLAND. OVER THREE HUNDRED REPLIES WERE RECEIVED WITHIN A 2½ WEEK PERIOD. THERE WERE NUMEROUS PHONE CALLS REQUESTING ADDITIONAL INFORMATION AND POSSIBLE FINANCIAL ASSISTANCE.

STIPENDS POLICY

GEORGETOWN AND CASS CONSIDERED THE FACT THAT MANY OF THE RESPITE PROGRAMS OPERATE ON VERY LIMITED BUDGETS. IT WOULD BE EXTREMELY DIFFICULT FOR CONSUMERS, PROVIDERS, PARENTS, AND SOME SMALL PROGRAMS TO MAKE A TRIP TO THE EAST COAST FOR THE CONFERENCE. TO ENCOURAGE MAXIMUM PARTICIPATION, IT WAS DECIDED TO OFFER A LIMITED NUMBER OF STIPENDS TO CONFERENCE PARTICIPANTS. AIRFARE OR TRAIN FARE IS USUALLY THE LARGEST EXPENDITURE. OFFERING TRAVEL REIMBURSEMENT STIPENDS WOULD HELP OFFSET THE TOTAL EXPENSE OF THE CONFERENCE PARTICIPANTS. PARTIAL STIPENDS (INCLUDING ROOM AND BOARD) WOULD POSSIBLY ENABLE MORE PERSONS TO ATTEND THE CONFERENCE.

THERE WERE EIGHT-FOUR REQUESTS FOR FINANCIAL ASSISTANCE FROM ALL OVER THE COUNTRY, (INCLUDING FIVE REQUESTS FROM THE STATE OF ALASKA ALONE). IN AN EFFORT TO AWARD THE STIPENDS ON AN EQUITABLE BASIS, GEORGETOWN FORMED A COMMITTEE TO DEVELOP CRITERIA AND MAKE SELECTIONS. THE FOLLOWING CRITERIA WERE USED TO REVIEW EACH APPLICATION:

1) APPLICANT'S STATEMENT OF NEED
2) TOTAL COST OF AIRFARE REIMBURSEMENT
3) GEOGRAPHIC LOCATION (URBAN/RURAL)
4) CONSIDERATION FOR MINORITY BASED PROGRAMS (E.G. NATIVE AMERICAN, BLACK, HISPANIC, OR ASIAN AMERICAN)

5) STATE REPRESENTATION AT CONFERENCE (THOSE PERSONS PRE-REGISTERED TO ATTEND FROM THAT SPECIFIC STATE)

6) APPLICANT SUMMARY OF THEIR PROGRAM AND/OR STATEMENT FOR WANTING TO ATTEND THE CONFERENCE.

THESE CRITERIA ARE NOT NECESSARILY LISTED IN ORDER OF PRIORITY. EACH APPLICATION WAS CONSIDERED INDIVIDUALLY BY THE STIPEND COMMITTEE MEMBERS.

<u>CONFERENCE PRESENTER SPONSORSHIP</u>

A NUMBER OF ORGANIZATIONS AND GROUPS ASSISTED IN PROVIDING MATERIALS AND FUNDING CONFERENCE PRESENTERS TO ATTEND. WE GREATLY APPRECIATE AND ACKNOWLEDGE THEIR SUPPORT:

CHILD DEVELOPMENT AND MENTAL RETARDATION CENTER (UAP)
UNIVERSITY OF WASHINGTON, SEATTLE, WASHINGTON

COLORADO DEVELOPMENTAL DISABILITIES COUNCIL, DENVER, COLORADO

DEVELOPMENTAL DISABILITIES LAW PROJECT, UNIVERSITY OF
MARYLAND LAW SCHOOL, BALTIMORE, MARYLAND

DHEW/OHD-DEVELOPMENTAL DISABILITIES OFFICE, WASHINGTON, D.C.

DISTRICT OF COLUMBIA DEVELOPMENTAL DISABILITIES COUNCIL,
WASHINGTON, D.C.

EASTERN NEBRASKA COMMUNITY OFFICE OF RETARDATION (ENCOR),
OMAHA, NEBRASKA

FAMILY AND CHILDREN'S SERVICES, CAMBRIDGE, MASSACHUSETTS

FEDERAL REGION III-OFFICE OF DEVELOPMENTAL DISABILITIES,
PHILADELPHIA, PENNSYLVANIA

FEDERAL REGION VII-OFFICE OF DEVELOPMENTAL DISABILITIES,
KANSAS CITY, MISSOURI

GEORGIA DEVELOPMENTAL DISABILITIES COUNCIL AND THE COASTAL
RESPITE PROJECT, BRUNSWICK, GEORGIA

IOWA DEVELOPMENTAL DISABILITIES COUNCIL, DES MOINES, IOWA

JOINT COMMISSION ON ACCREDITATION OF HOSPITALS, AC/MR-DD,
CHICAGO, ILLINOIS

KANSAS DEVELOPMENTAL DISABILITIES COUNCIL, TOPEKA, KANSAS

KANSAS UNIVERSITY AFFILIATED FACILITY (UAP), LAWRENCE, KANSAS

LOUISIANA OFFICE OF MENTAL RETARDATION, BATON ROUGE, LOUISIANA

MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL AND THE
RESPITE CARE POLICY DEVELOPMENT PROJECT, BOSTON, MASSACHUSETTS

NATIONAL COUNCIL OF HOMEMAKER/HOME HEALTH AIDE SERVICES,
NEW YORK, NEW YORK

THE NATIONAL CHAPTER OF THE AMERICAN RED CROSS, WASHINGTON, D.C.

Format and Agenda

The conference brochure was finalized and mailed out to responding parties on April 10, 1978. (see attachment). The conference format allowed for intensive experiences for participants with many opportunities for:

1) active participation in forum discussions, audience response sessions and major strategy planning;
2) discussing community-based temporary family support systems with presenters in small workshop sessions; and
3) examining the critical national issues of funding, legislation and regulatory development with federal administrators, national authorities and consumers.

CASS successfully recruited thirty persons to represent their individual programs and to share needed information and skills at the conference. The presenting programs were divided into the following eight categories (referred to as tracks) which represent different core components of an integrated community-based family support system model. They are:

1) Parent Support Groups and Personal Advocacy
2) Homemaker/Home Health Aide Services
3) State Agency Systems
4) Training: Personnel Preparation-Parent/In Home
5) Temporary Foster Care and Generic Agency Development
6) Core Residential Programs
7) Family Resources Services and Ancillary Supports
8) Companion and Sitter Services

Each speaker repeated his/her presentation four times during the two day. This enabled persons attending the conference to maximize participation and interaction with the presenting program representatives. Georgetown provided duplicating services for all programs which needed materials distributed (e.g. small proposals, organizational charts, forms, program descriptions, etc.).

Agenda

The following is a list of program representatives who delivered workshops during the conference. Each program listed has some innovative or unique approach to providing family support services.

Parent Support Groups and Personal Advocacy

* RANDY KITCH, KANSAS COORDINATOR
  PEOPLE FIRST
  816 LANE
  TOPEKA, KANSAS

* PATTY SMITH, REGIONAL COORDINATOR
  PILOT PARENT PROGRAM
  GREATER OMAHA ASSOCIATION FOR RETARDED CITIZENS (GOARC)
  3212 DODGE
  OMAHA, NEBRASKA

Homemaker and Home Health Aide Services

* VIRGINIA ATTRIDGE, DIRECTOR
  HOME AIDES OF CENTRAL NEW YORK
  550 MIDTOWN PLAZA-EAST WATER STREET
  SYRACUSE, NEW YORK 13210

* PEGGY HALPERN, REPRESENTATIVE
  HOME SERVICES ASSOCIATION OF ST. PAUL, MINNESOTA
  2716 ST. PAUL STREET
  BALTIMORE, MARYLAND 21218

* MARY HILL, ADMINISTRATOR
  FAMILY CARE CONTRACT
  VISITING NURSE ASSOCIATION OF DALLAS
  4606 GREENVILLE AVENUE
  DALLAS, TEXAS 72506

State Agency Systems

* LOLA BUSENBARRICK, SUPERVISOR
  DAY DEVELOPMENTAL TRAINING SERVICES
  LOUISIANA OFFICE OF MENTAL RETARDATION
  721 GOVERNMENT STREET
  BATON ROUGE, LOUISIANA 70804

* BARBARA HOUGH, ADMINISTRATOR
  HOME AID RESOURCES PROGRAM
  BUREAU OF DEVELOPMENTAL DISABILITIES
  M.S. 421
  OLYMPIA, WASHINGTON 98504

Training Personnel Preparation-Parent/In Home

* ALBERT CALELLO, EXECUTIVE DIRECTOR
  CAMBRIDGE FAMILY AND CHILDREN
  99 BISHOP RICHARD ALLEN DRIVE
  CAMBRIDGE, MASSACHUSETTS 02139

* MARSHA DAKE, DIRECTOR
  PROGRAM DEVELOPMENT
  NURSING AND HEALTH PROGRAM
  AMERICAN RED CROSS NATIONAL HEADQUARTERS
  WASHINGTON, D.C. 20006

* GENE EDGAR, DIRECTOR
  RESPITE PROVIDER TRAINING PROJECT
  103 MILLER HALL, DQ-12
  UNIVERSITY OF WASHINGTON
  SEATTLE, WASHINGTON 98195

* DENNIS GERBER, COORDINATOR
PROJECT H.E.L.O.
CAMBRIDGE FAMILY AND CHILDREN'S SERVICES
99 BISHOP RICHARD ALLEN DRIVE
CAMBRIDGE, MASSACHUSETTS 02139

* GRATIA KOCH, COORDINATOR
F.A.C.T. PROJECT
SYSTEMS UNLIMITED
1020 WILLIAM STREET
IOWA CITY, IOWA 52240

* KIM SNYDER, DEVELOPMENTAL THERAPIST
PROJECT H.E.L.O.
CAMBRIDGE FAMILY AND CHILDREN'S SERVICES
99 BISHOP RICHARD ALLEN DRIVE
CAMBRIDGE, MASSACHUSETTS 02139

Temporary Foster Care and Generic Agency Development

* CARY CARRON, DIRECTOR
RESPITE SERVICES PROJECT
ARCHDIOCESE OF DENVER
2141 SOUTH ZENOBIA STREET
DENVER, COLORADO 80219

* MIDGE MINTUN, ADMINISTRATIVE SUPERVISOR
KANSAS CHILDREN'S SERVICE LEAGUE
TOPEKA DISTRICT
P.O. BOX 5314
TOPEKA, KANSAS 66605

Companion/Sitter Services

* MARY JIM MARTIN, DIRECTOR
SOCIAL SERVICES AND RESPITE SERVICE PROJECT
SAN DIEGO ASSOCIATION FOR RETARDED CITIZENS
3035 G STREET
SAN DIEGO, CALIFORNIA 92102

* DEANNA SHOOB, PRESIDENT
CHILDCARE ASSISTANCE PROGRAM FOR SPECIAL CHILDREN (CAPS)
P.O. BOX 1217
SPRINGFIELD, VIRGINIA 22151

Core Residential Programs

* CHUCK BALLANCE, DIRECTOR
COASTAL HOME RESPITE CARE PROJECT
GLYNN COUNTY MENTAL HEALTH/MENTAL RETARDATION CENTER
1609 NEWCASTLE STREET
BRUNSWICK, GEORGIA 31520

* PAT MCMAHON, PROJECT DIRECTOR
ESPERANZA PARA NUESTRAS NINOS
1330 VALDORA, S.W.
P. O. BOX 12212
ALBUQUERQUE, NEW MEXICO 87105

Family Resource Services and Ancillary Supports

* KAY CAPINO, PEDIATRIC CLINICAL NURSE SPECIALIST
COMMUNITY NURSING AND DEVELOPMENTAL PROGRAM
DIVISION OF MENTAL RETARDATION
BIGGS BUILDING, DELAWARE STATE HOSPITAL
NEW CASTLE, DELAWARE 19720

- JOANNA E. MCCABE, DIRECTOR
  NURSING AND COTTAGE LIFE
  DIVISION OF MENTAL RETARDATION
  ROUTE 1, BOX 1000
  GEORGETOWN, DELAWARE 19947

- HELEN SMIDDY, COORDINATOR
  COMMUNITY NURSING AND DEVELOPMENTAL PROGRAM
  DIVISION OF MENTAL RETARDATION
  BIGGS BUILDING
  DELAWARE STATE HOSPITAL
  NEW CASTLE, DELAWARE 19720

- MARIANNE SMITH, RESPITE COORDINATOR
  COMMUNITY NURSING AND DEVELOPMENTAL PROGRAM
  DIVISION OF MENTAL RETARDATION
  ROUTE 1, BOX 1000
  GEORGETOWN, DELAWARE 19947

IN ADDITION TO THE CONCURRENT WORKSHOP SESSIONS, THERE WERE FOUR MAJOR FORUM SESSIONS AND A STRATEGY/RECOMMENDATION SESSION WHICH CONCLUDED THE CONFERENCE. THE FOLLOWING IS A LISTING OF EACH FORUM AND THOSE PERSONS WHO WERE SPEAKERS OR SERVED ON PANELS:

FORUM I THE NATIONAL PERSPECTIVE

KEYNOTE ADDRESS: DORIS HAAR
DIRECTOR OF RESEARCH AND DEVELOPMENT
DEVELOPMENTAL DISABILITIES OFFICE
MARY SWEITZER BUILDING
330 C STREET, S.W., ROOM 3415
WASHINGTON, D.C. 20201

REPORT OF THE NATIONAL RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

E. WADE HITZING, PH.D., DIRECTOR
BERTINE LOOP, PROJECT COORDINATOR
CENTER FOR THE DEVELOPMENT OF COMMUNITY
ALTERNATIVE SERVICE SYSTEMS (CASS)
4500 EMILE STREET
BOX 223, ROOM 4022
OMAHA, NEBRASKA 68105

FORUM II THE IMPACT OF LEGISLATION, LITIGATION, REGULATIONS, AND STANDARDS ON THE DEVELOPMENT OF INTEGRATED FAMILY SUPPORT SYSTEMS

MARCIA PEARCE BURGDORF, DIRECTOR
DEVELOPMENTAL DISABILITIES LAW PROJECT
UNIVERSITY OF MARYLAND LAW SCHOOL
500 WEST BALTIMORE
BALTIMORE, MARYLAND 21201

EMILY LAYZER, STAFF ASSOCIATE
ACCREDIATATION PROGRAM
NATIONAL COUNCIL FOR HOMEMAKER/HOME HEALTH
AID SERVICES, INC.
67 IRVING PLACE
NEW YORK, NEW YORK 10003

BARRY MINZER, LEGAL CONSULTANT
MASSACHUSETTS RESPITE CARE POLICY
DEVELOPMENT PROJECT
110 TREMONT STREET - 6TH FLOOR
BOSTON, MASSACHUSETTS 02108

TED TAYLOR, DIRECTOR
ACCREDIATION COUNCIL/MR-DD
JOINT COMMISSION ON ACCREDITATION OF HOSPITALS
875 NORTH MICHIGAN AVENUE
CHICAGO, ILLINOIS 60611

FORUM III CONSUMERISM: CORNERSTONE TO DEVELOPMENT OF FAMILY CENTERED SUPPORT SYSTEMS

LOUISE BREDDON
440 HOLLY HILL ROAD
UNIVERSITY PARK, MARYLAND 20782

MAUREEN WINN, LEGISLATIVE CHAIRPERSON
MASSACHUSETTS COUNCIL OF THE HANDICAPPED
10 WEST CHARDON ROAD
WINCHESTER, MASSACHUSETTS 01390

FORUM IV FEDERAL AND ADMINISTRATION COMMITMENT TO STABLE FUNDING FOR TEMPORARY FAMILY SUPPORT SYSTEMS

PANELISTS:

MS. JOHNNIE V. BROOKS
DIRECTOR, ADMINISTRATION FOR PUBLIC SERVICES - TITLE XX - DHEW
330 C STREET, S.W.
WASHINGTON, D.C. 20201

BILL HILLMAN
BUREAU OF EDUCATION OF THE HANDICAPPED (BEH)
DHEW, DIVISION OF PERSONNEL PREPARATION
DONAHOE BUILDING
400 MARYLAND AVENUE, S.W.
WASHINGTON, D.C. 20202

ALFREDO ROTUNDO
DIRECTOR, REHABILITATIVE SERVICES ADMINISTRATION (RSA)
DHEW, OFFICE OF FINANCIAL OPERATION
MARY SWEITZER BUILDING
300 C STREET, S.W.
WASHINGTON, D.C. 20201

MODERATOR:

ERNEST MIDDLETON
GEORGETOWN HEALTH CAREERS PROGRAM
2233 WISCONSIN AVENUE, N.W., SUITE 537
WASHINGTON, D.C. 20007

CONSUMER RESPONDENTS:

RANDY KITCH
PEOPLE FIRST
816 LANE
TOPEKA, KANSAS

PEG MORTON
MONTGOMERY COUNTY ASSOCIATION FOR RETARDED CITIZENS (MCARC)
11212 NORRIS DRIVE
SILVER SPRING, MARYLAND 20902

PATTI SMITH
PILOT PARENTS
GREATER OMAHA ASSOCIATION FOR RETARDED CITIZENS
3212 DODGE
OMAHA, NEBRASKA 68131

MAUREEN WINN
MASSACHUSETTS COUNCIL FOR THE HANDICAPPED
10 WEST CHARDON ROAD
WINCHESTER, MASSACHUSETTS 01890

COMMUNICATION RESOURCE CENTER

DURING THE CONFERENCE, A SPECIAL ROOM WAS DESIGNATED AS A COMMUNICATION RESOURCE CENTER. THIS ROOM WAS MADE AVAILABLE ON AN ON-GOING BASIS FOR DISPLAYING MATERIALS OR VIEWING FILMS, VIDEO AND SLIDE-TAPE PRODUCTIONS. THE INSTRUCTIONAL TECHNOLOGIST FROM GEORGETOWN VOLUNTEERED HER TIME AND EXPERTISE TO ORGANIZE THE SPACE AND MAINTAIN THE VIEWING SCHEDULE. THERE WERE OTHER RESOURCE MATERIALS WITH LISTS TO REQUEST ADDITIONAL INFORMATION. THE FOLLOWING LIST IS COMPRISED OF THE FILMS AND SLIDE-TAPE PRODUCTIONS CREATED BY INDIVIDUAL PROGRAMS:

PILOT PARENTS
SLIDE/TAPE-12 MINUTES
FROM PILOT PARENTS
OMAHA, NEBRASKA

PEOPLE FIRST
16 MM-45 MINUTES
FROM KANSAS UAF, M.C.R.I.

ESPERANZA
SLIDE/TAPE-15 MINUTES
FROM ESPERANZA PARA LOS NINOS
ALBUQUERQUE, NEW MEXICO

TRAINING VIDEO TAPES
VIDEO
FROM SAN DIEGO ARC
SAN DIEGO, CALIFORNIA

A BETTER ANSWER
16 MM-10 MINUTES
FROM NATIONAL COUNCIL
HOMEMAKER-HOME HEALTH AIDES

LOOKING UP TOGETHER
SLIDE/TAPE-12 MINUTES
FROM ENCOR
(AVAILABLE THROUGH CASS)

WHAT IS ENCOR?
SLIDE/TAPE-26 MINUTES
FROM ENCOR-EARLY EDUCATION (CASS)

YOUR ARE OUR CHILD
SLIDE/TAPE-16 MINUTES
FROM ENCOR (CASS)

HANDICAPISM
SLIDE/TAPE-28 MINUTES
FROM CASS

CRY SORROW, CRY HOPE
16 MM-60 MINUTES
FROM PILOT PARENTS
OMAHA, NEBRASKA

CONFERENCE ATTENDANCE AND STATE REPRESENTATION

THERE WAS AN OVERWHELMING RESPONSE TO THE CONFERENCE. TOTAL ATTENDANCE WAS OVER 160 PARTICIPANTS DURING THE TWO DAYS. THERE WERE ONLY TWELVE STATES WHICH WERE NOT REPRESENTED AT THE CONFERENCE. THOSE STATES WERE:

- ARKANSAS
- FLORIDA
- HAWAII
- IDAHO
- NEVADA
- NORTH DAKOTA
- OKLAHOMA
- SOUTH CAROLINA
- SOUTH DAKOTA
- TENNESSEE
- UTAH
- WYOMING

Other states, excluding the District of Columbiz, that had a high rate of participation include: Massachusetts with 21 participants, Maryland with 19, Virginia with 19, Virginia with 9, and Pennsylvania and New York with 8 respectively. In addition to the 35 conference participants from the District of Columbia, 27 faculty members from the Georgetown Child Development Center attended during the 2 days. The following chart graphically illustrates state representation at the conference.

CONFERENCE ATTENDANCE BY STATES

STATE	PARTICIPANTS	STATE	PARTICIPANTS
ARIZONA	1	MONTANA	1
ALABAMA	1	NEBRASKA	6
ALASKA	2	NEVADA	0
ARKANSAS	0	NEW HAMPSHIRE	2
CALIFORNIA	3	NEW JERSEY	3
CONNECTICUT	1	NEW MEXICO	1
COLORADO	2	NEW YORK	8
DISTRICT OF COLUMBIA	35	NORTH CAROLINA	5
DELAWARE	5	NORTH DAKOTA	0
FLORIDA	0	OHIO	1
GEORGIA	2	OKLAHOMA	0
HAWAII	0	OREGON	1
IDAHO	0	PENNSYLVANIA	8
ILLINOIS	2	RHODE ISLAND	2
INDIANA	2	SOUTH CAROLINA	0
IOWA	5	SOUTH DAKOTA	0
KANSAS	4	TENNESSEE	0
KENTUCKY	1	TEXAS	1
LOUISIANA	2	UTAH	0
MAINE	1	VERMONT	1
MARYLAND	19	VIRGINIA	9
MASSACHUSETTS	21	WASHINGTON	2
MICHIGAN	4	WEST VIRGINIA	3
MINNESOTA	5	WISCONSIN	3
MISSISSIPPI	1	WYOMING	0
MISSOURI	5		

CONFERENCE EVALUATION: PARTICIPANT INFORMATION SUMMARY

THE CONFERENCE EVALUATION FORMS REVEALED SOME PARTICULARLY INTERESTING DATA. ACCORDING TO THE TABULATED RESPONSE, THE AVERAGE CONFERENCE PARTICIPANT WAS A FEMALE SERVICE PROVIDER, HAVING BETWEEN TWO AND FIVE YEARS EXPERIENCE AND WORKING IN AN URBAN SETTING. CATEGORICALLY, THE DATA IS AS FOLLOWS:

SEX

FEMALES OUTNUMBERED MALE PARTICIPANTS 2-1. THERE SEEMED TO BE FEW MALES INVOLVED IN DIRECT SERVICES (E.G.: CARETAKER/THERAPIST/ RESPITE PROVIDER, ETC.). THE MALES WERE PRIMARILY ADMINISTRATORS, AGENCY DIRECTORS, OR HIGH LEVEL STATE AND FEDERAL EMPLOYEES. IN CONTRAST, THE FEMALES SPANNED THE ENTIRE LINE OF SERVICES. SOME WERE RESPITE PROVIDERS AND HOMEMAKERS WHILE OTHERS WERE INVOLVED IN HIGHLY SPECIALIZED TRAINING AND TECHNICAL ASSISTANCE. THE DATA FURTHER INDICATED THAT MANY FEMALES ASSUMED OTHER DIVERSE ROLES SUCH AS PRESIDENTS OF SMALL COMMUNITY-BASED PROGRAMS, DIRECTORS OF STATE AND LOCAL AGENCIES, PROGRAM CONSULTANTS, REGIONAL LICENSING AND STANDARDS SPECIALISTS, AND PARENT LOBBYISTS/ACTIVISTS.

TYPE OF PARTICIPANT

DATA SHOWS THAT SERVICE PROVIDERS OUTNUMBERED CONSUMERS, PARENTS, AND OTHER PARTICIPANTS BY 8-1. AMONG THE FORMS COMPLETED THERE WERE FORTY SERVICE PROVIDERS, FIVE PARENTS, THREE CONSUMERS, AND ELEVEN IN OTHER CATEGORIES. THIS HAS MANY FAR REACHING IMPLICATIONS THAT REFLECTS ON CONFERENCE ADVERTISEMENT AND RECRUITMENT TECHNIQUES. THE MAJORITY OF CONFERENCE ANNOUNCEMENTS WERE SENT OUT TO AGENCIES, ASSOCIATIONS, INSTITUTIONS, CONSUMER GROUPS, DEVELOPMENTAL DISABILITY COUNCIL MEMBERS, SMALL PROGRAMS, AND OTHERS ON BOTH THE GEORGETOWN AND CASS MAILING LISTS. THIS INFORMATION MAY NOT HAVE BEEN FILTERED THROUGHOUT THE TOTAL COMMUNITY TO SOLICIT SUPPORT AND PARTICIPATION FROM PRIMARY CONSUMERS AND THEIR FAMILIES.

ONE OF THE MAJOR RECOMMENDATIONS FROM THE CONSUMERISM AND COMMUNITY MOBILIZATION SESSION WAS TO SEEK MORE CONSUMER AND FAMILY REPRESENTATION AT ALL MAJOR CONFERENCES. SINCE THIS IS USUALLY A

LARGE EXPENSE, IT WAS FURTHER RECOMMENDED THAT SUPPLEMENTAL FUNDING FROM VARIOUS AGENCIES BE PROVIDED TO COVER OR OFFSET CONSUMER COSTS.

PARTICIPATION BY PRIMARY CONSUMERS AND THEIR FAMILY MEMBERS IS AN INTEGRAL PART OF ANY SERVICE ORIENTED PROJECT FOR HANDICAPPED PERSONS. THE CONFERENCE DID TRY TO MEET THIS NEED BY PROVIDING TRAVEL REIMBURSEMENT TO SOME CONFERENCE PARTICIPANTS (SEE ATTACHMENT).

YEARS OF EXPERIENCE

AS STATED PREVIOUSLY, THE AVERAGE PARTICIPANT HAD BETWEEN TWO-FIVE YEARS OF EXPERIENCE IN ANY ASPECT OF THE FIELD. THE DATA INDICATED 14 PERSONS HAVING 0-1 YEARS OF EXPERIENCE; 24 PERSONS HAVING 2-5 YEARS; 7 PERSONS HAVING 6-10 YEARS; AND ONLY 1 PERSON WITH MORE THAN 10 YEARS.

THIS DATA SHOWS THAT THERE WERE FEW FORMALLY ORGANIZED RESPITE OR FAMILY SUPPORT SYSTEMS IN EXISTENCE FOR MORE THAN 10 YEARS. ALTHOUGH HANDICAPPED PERSONS AND THEIR FAMILIES HAVE BEEN IN DIRE NEED OF THESE SERVICES, IT ISN'T UNTIL RECENTLY THAT THIS FIELD IS BEGINNING TO EVOLVE TO MEET THESE NEEDS. ONE OF THE PRIMARY REASONS FOR SPONSORING THE CONFERENCE WAS TO BRING THIS LONG NEGLECTED AREA TO THE NATIONAL ARENA.

GEOGRAPHIC AREA SERVED

SERVICES OFFERED IN URBAN SETTINGS OUTNUMBERED RURAL 3-2. THERE WERE 33 RESPONSES FOR URBAN, 22 FOR RURAL, AND 5 FOR SUBURBAN. IT SHOULD BE NOTED THAT 15 PERSONS INDICATED THAT THEY SERVED BOTH RURAL AND URBAN POPULATIONS.

PARTICIPANT INFORMATION SUMMARY

(NOTE: IF ALL NUMBERS IN CATEGORIES DO NOT ADD UP TO SIXTY-THREE, MANY ITEMS WERE LEFT INCOMPLETE ON THE EVALUATIONS FORMS.)

TYPE OF PARTICIPANT

PARENT	5
CONSUMER	3
SERVICE PROVIDERS	40
OTHER	11

YEARS OF EXPERIENCE

0-1 YRS.	14
2-5 YRS.	24
6-10 YRS.	7
10 YRS & OVER	1

SEX

MALE	18
FEMALE	39

GEOGRAPHIC AREA SERVED

URBAN	33
RURAL	22
SUBURBAN	5

NATIONAL RECOMMENDATIONS AND STRATEGY PLANNING

THE LAST SESSION OF THE CONFERENCE WAS A MAJOR STRATEGY PLANNING SESSION AT WHICH PARTICIPANTS SELECTED ONE OF THE FOLLOWING FOUR GROUPS TO ATTEND:

- COMMUNICATION NETWORK DEVELOPMENT
- CONSUMERISM
- FUNDING
- LEGISLATION

IN EACH GROUP DISCUSSIONS LED TO A LISTING OF MAJOR POLICY RECOMMENDATIONS AND METHODS OF IMPLEMENTATION TO BENEFIT RESPITE SERVICES AND TEMPORARY FAMILY SUPPORT SYSTEMS ON A NATIONAL LEVEL.

COMMUNICATION NETWORK

NATIONAL LEVEL

1) BEGIN A NATIONAL NEWSLETTER, WITH INPUT FROM ALL STATES, TO GIVE CURRENT INFORMATION ON EXISTING RESPITE CARE PROGRAMS AND OTHER TEMPORARY FAMILY SUPPORT SYSTEMS (E.G. NEW LEGISLATION, LOBBYING EFFORTS AND RESULTS, FUNDING OPTIONS (RFP), ETC.

2) LINK WITH AN ALREADY EXISTING NATIONAL NEWSLETTER SUCH AS NATIONAL ASSOCIATION FOR RETARDED CITIZENS (NARC), AMERICAN ASSOCIATION FOR MENTAL DEFICIENCY (AAMD), DEVELOPMENTAL DISABILITIES, ETC.

3) ASSIGN RESPONSIBILITY TO THE CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS (CASS) FOR COMPILING AND DISSEMINATING THE NEWSLETTER. THERE SHOULD BE A SUBSCRIPTION FEE ESTABLISHED TO OFFSET THE COST OF PRINTING, DUPLICATION, AND MAILING.

4) DEVELOP A NATIONAL DIRECTORY OF SERVICES TO ENCOURAGE PROGRAM IDENTIFICATION AND COMMUNICATION. THE DIRECTORY WOULD GIVE A LISTING OF ALL PROGRAMS, CATEGORIZE THEM BY DESCRIPTION OF SERVICES PROVIDED, LIST A CONTACT PERSON, ADDRESS AND PHONE NUMBER. THIS WOULD BE PRINTED, DISTRIBUTED, AND UPDATED ON AN ANNUAL BASIS.

5) PLAN A SECOND NATIONAL CONFERENCE. TO ENCOURAGE MAXIMUM ATTENDANCE AND PARTICIPATION, COORDINATE THE SECOND CONFERENCE WITH ANOTHER MAJOR CONFERENCE SUCH AS THE AMERICAN ASSOCIATION OF MENTAL DEFICIENCY (AAMD), COUNCIL FOR EXCEPTIONAL CHILDREN (CEC), NATIONAL ASSOCIATION FOR RETARDED CITIZENS (NARC), OR PRESIDENT'S COUNCIL ON MENTAL RETARDATION.

   DISSEMINATE THE REPORT FROM THE CONFERENCE INCLUDING:

   A) CONFERENCE PARTICIPANTS
   B) NATIONAL RECOMMENDATIONS
   C) CONFERENCE EVALUATION RESULTS.

STATE LEVEL

6) DESIGNATE OR ELECT ONE STATE REPRESENTATIVE WHO WILL BE RESPONSIBLE FOR COLLECTING AND DISSEMINATING INFORMATION THROUGHOUT THE STATE ON ALL ASPECTS OF RESPITE SERVICES AND TEMPORARY FAMILY SUPPORT SYSTEMS.

A) STATE REPRESENTATIVE WOULD CONTACT THEIR INDIVIDUAL STATE DEVELOPMENTAL DISABILITIES COUNCILS AND SERVE ON STATE DEVELOPMENTAL DISABILITIES COMMITTEES.
B) STATE REPRESENTATIVES SHOULD SERVE AS A LOBBYIST FOR DEVELOPMENTAL DISABILITY SUPPORT OF RESPITE CARE AND TEMPORARY FAMILY SUPPORT SYSTEMS.

7) STATES SHOULD DEVISE A MECHANISM FOR DISSEMINATING INFORMATION THROUGHOUT THEIR STATES.

8) STATES SHOULD GIVE STATEWIDE CONFERENCES AND SOLICIT THE SUPPORT OF DEVELOPMENTAL DISABILITIES COUNCILS, ASSOCIATIONS, AND OTHER AGENCIES.

9) LOBBY FOR STATE DEVELOPMENTAL DISABILITY FUNDS TO HELP SPONSOR STATE CONFERENCES OR SEND REPRESENTATIVES TO THE SECOND NATIONAL CONFERENCE.

CONSUMERISM

1) EDUCATE CONSUMERS AND THEIR FAMILIES ABOUT THEIR LEGAL RIGHTS UNDER SPECIFIC LEGISLATION THAT AFFECTS HANDICAPPED PERSONS (P.L. 94-142, ETC.).

2) SEEK MORE REPRESENTATION BY CONSUMERS AND THEIR FAMILIES AT ALL CONFERENCES OF NATIONAL SIGNIFICANCE.

3) SEEK MORE REPRESENTATION BY CONSUMERS AND THEIR FAMILIES ON PUBLIC ADVISORY COMMITTEES (LOCAL AND STATE LEVEL).

4) SEEK FUNDS TO PAY EXPENSES OF CONSUMER ACTIVITIES WHILE PARTICIPATING IN NATIONAL SIGNIFICANCE CONFERENCES AND MEETINGS.

5) FORM A COALITION, AT THE LOCAL, STATE, AND NATIONAL LEVEL, A SINGLE UMBRELLA GROUP OF CONSUMERS AND THEIR FAMILIES WHICH WOULD SPAN AND REPRESENT THE DIFFERENT HANDICAPPING CONDITIONS.

6) LEADERSHIP IN THE COALITION SHOULD BE HELD BY CONSUMERS AND THEIR FAMILIES.

7) THE COALITION SHOULD HAVE A FULL-TIME POLITICAL LOBBY AT THE STATE AND NATIONAL LEVELS.

8) EMPHASIZE AND EXPOSE THE ABILITIES OF HANDICAPPED PEOPLE THROUGH MANY DIFFERENT CHANNELS.

9) MAKE MILITANT USE OF THE MEDIA THROUGH COMMUNITY SERVICES ANNOUNCEMENTS (E.G. RADIO, TELEVISION, CINEMA, NEWSPAPERS, COMMUNITY BULLETINS, ETC.).

10) ENCOURAGE THE MAKING OF GRANTS DIRECTLY TO CONSUMERS AND THEIR FAMILIES TO PURCHASE SERVICES FOR THEMSELVES.

FUNDING

1) THE FUNDING OF PROGRAMS SHOULD BE PREDICATED UPON A SECURE CONTINUING LOCAL OR STATE FUNDING BASE.

2) FEDERAL GRANT FUNDING BE AVOIDED, EXCEPT AS AN ELEMENT OF NECESSARY "DEMONSTRATION" OR "START-UP" COSTS.

3) THE DEVELOPMENTAL DISABILITIES OFFICE, OR THE OTHER APPROPRIATE FEDERAL AGENCY OR AGENCIES, PROVIDE NATIONAL LEVEL FUNDING FOR A PROJECT TO PROVIDE TECHNICAL AND INFORMATIONAL ASSISTANCE ON RESPITE PROGRAMMING AT THE NATIONAL LEVEL.

4) A NATIONAL SURVEY OF FUNDING SOURCES APPROPRIATE FOR THE SUPPORT OF RESPITE SERVICES PROGRAMS BE COMPILED.

5) A NATIONAL RESPITE INFORMATION EXCHANGE BE ESTABLISHED AND FUNDED BY THE FEDERAL GOVERNMENT.

6) ALL APPROPRIATE LEGISLATIVE, REGULATORY, AND EXECUTIVE ACTION BE TAKEN AT THE FEDERAL, STATE, AND LOCAL LEVEL TO INSURE THAT RESPITE PROGRAMMING BECOMES A FUNDING PRIORITY SERVICE IN ALL JURISDICTIONS.

7) ALL TECHNICAL ASSISTANCE AND TRAINING PROGRAMS CURRENTLY IN EXISTENCE, AND PARTICULARLY THOSE SUPPORTED THROUGH THE UNIVERSITY AFFILIATED PROGRAMS (UAP) DEVELOP APPROPRIATE FAMILIARITY WITH THE TRAINING AND OUTREACH PROGRAMMING IN THE AREA OF RESPITE SERVICES AND CONSUMER-CENTERED FAMILY SUPPORT SYSTEMS.

LEGISLATION

1) INTRODUCE FEDERAL AND STATE LEGISLATION TO BE IMMEDIATELY ENACTED UPON WHICH SPEAKS TO FAMILY SUPPORT SERVICES AND APPROPRIATES REASONABLE MONIES TO IMPLEMENT THE SAME.

2) OFFER SUPPORT TO CURRENT LEGISLATIVE EFFORTS PARTICULARLY IN THE AREAS OF:

   A) DEINSTITUTIONALIZATION
   B) NORMALIZATION
   C) LEAST RESTRICTIVE ALTERNATIVE
   D) PUBLIC LAW 94-142 AND PUBLIC LAW 94-103
   E) HUMAN RIGHTS LEGISLATION.

3) RAISE TITLE XX CEILING AND ELIMINATE BARRIERS TO ITS USE FOR FAMILY SUPPORT SERVICES.

4) STRONGLY SUPPORT THE FRAZIER-KEYS BILL.

5) HELP THE FEDERAL, STATE, AND LOCAL POLICY AND FISCAL BODIES TO UNDERSTAND PREVENTION AS WELL AS CRISIS AND "BANDAID" PROGRAMS.

6) ENCOURAGE MAXIMUM SUPPORT FOR ALL LEGISLATIVE EFFORTS TO RECOGNIZE "PEOPLE" RATHER THAN "PROBLEMS".

CONFERENCE EVALUATION

THE CONFERENCE GENERALLY RECEIVED POSITIVE EVALUATIONS FROM PARTICIPANTS. MOST PARTICIPANTS FELT THERE WAS A SERIOUS NEED FOR AN ANNUAL CONFERENCE TO PROVIDE A BROADER FORUM TO DISCUSS THE FULL RANGE OF FAMILY SUPPORT SERVICES.

SOME STATED THAT THIS WAS A FIRST STEP IN ORGANIZING NATIONAL AWARENESS AND SUPPORT FOR RESPITE SERVICES. OTHERS EXPRESSED FEELINGS OF "OPERATING IN A VACUUM" AND THAT THE CONFERENCE HELPED EASE THEIR SENSE OF ISOLATION AND FRUSTRATION. IT IS PARTICULARLY INTERESTING TO NOTE THAT, PRIOR TO THE CONFERENCE, MANY PARTICIPANTS HAD NEVER MET OTHER RESPITE PROVIDERS FROM THEIR OWN COMMUNITY AND STATE. SOME WERE SURPRISED TO FIND THAT THERE WERE MANY OTHER PROGRAMS SIMILAR TO THEIR OWN ACROSS THE COUNTRY AND THAT THEY WERE OFTEN REPRESENTED IN THE WORKSHOP SESSIONS.

THE CONFERENCE EVALUATION INCLUDED A SECTION WHICH REQUIRED WRITTEN RESPONSES TO THIS QUESTION - WHAT FUTURE TRAINING AND TECHNICAL ASSISTANCE NEEDS DO YOU SEE FOR STATES TO IMPLEMENT PROGRAMS OF RESPITE CARE AND TEMPORARY FAMILY SUPPORTS?

MANY OF THE PARTICIPANTS TOOK THIS AS AN OPPORTUNITY TO EXPRESS THEIR FEELINGS, CONCERNS AND TO GIVE SUGGESTIONS. THE PARTICIPANTS' RESPONSES TENDED TO BE EXTREMELY LENGTHY. THE STATEMENTS MADE MOST FREQUENTLY AND THOSE WHICH WERE MOST PERTINENT WERE EDITED. THE FOLLOWING GENERAL NEEDS STATEMENTS ARE REPRESENTATIVE OF THE INDIVIDUAL PARTICIPANTS COMMENTS REGARDING THEIR FUTURE TECHNICAL ASSISTANCE AND TRAINING NEEDS:

COMMUNICATIONS NETWORK DEVELOPMENT

- DEVELOP AND COORDINATE HIGHLY STRUCTURED STATE AND LOCAL COMMUNICATION NETWORKS.
- DEVELOP MECHANISMS FOR EFFECTIVE DISSEMINATION OF FEDERAL AND STATE LEVEL INFORMATION TO LOCAL GRASS-ROOTS CONSUMER ORGANIZATIONS.
- COMPILE AND DISSEMINATE A NATIONAL RESOURCE LIST OF REPRESENTATIVE COMMUNITY-BASED RESPITE AND TEMPORARY FAMILY SUPPORT SERVICE PROGRAMS.
- DEVELOP AND COORDINATE NATIONAL AND STATE CONFERENCES ON COMMUNITY-BASED TEMPORARY FAMILY SUPPORTS AND RESPITE SERVICE SYSTEMS.
- PLAN ADDITIONAL NATIONAL LEVEL MEETINGS AND CONFERENCES THAT EMPHASIZE BROADER REPRESENTATION FROM CONSUMERS, FAMILIES, AND GENERIC LOCAL, STATE AND FEDERAL PROGRAMS.

COMMUNITY MOBILIZATION

- FORM A NATIONAL COALITION OF STATE AND LOCAL REPRESENTATIVE GROUPS.
- SEEK FUNDS FOR FEDERAL LEVEL TECHNICAL ASSISTANCE PROJECT TO: SERVE AS RESOURCE TO AGENCIES AND GROUPS ACTING TO IMPLEMENT COMMUNITY-BASED PROGRAMS OF TEMPORARY FAMILY SUPPORT; AND DEVELOP STRATEGIES AT NATIONAL, STATE AND LOCAL LEVELS.
- DEVELOP A POLITICAL BASE FOR MOBILIZING FULL-TIME LOBBY EFFORTS AT BOTH THE NATIONAL AND STATE LEVELS.

LINKAGES WITH EXISTING RESOURCES

- SEEK SPONSORSHIP OF RESPITE AND FAMILY SUPPORT PROGRAM IN UMBRELLA HUMAN RESOURCE AGENCIES. (NOTE: MANY SPECIALIZED PROGRAMS PROVIDE SUPPORTS THAT ARE OTHERWISE AVAILABLE AND MANDATED IN THE BROADER PUBLIC SECTOR)
- SEEK SUPPORT AND RECOGNITION FROM STATE LEVEL DEPARTMENTS TO PROVIDE DATA, TRAINING, AND RESOURCE INFORMATION TO FAMILIES WHO COULD BENEFIT FROM TEMPORARY FAMILY SUPPORT SERVICES.
- OBTAIN TECHNICAL ASSISTANCE AND TRAINING TO DEVELOP STATE PLANS AND/OR STRATEGIES SPECIFIC TO THE SOCIAL AND POLITICAL CLIMATE UNIQUE TO EACH INDIVIDUAL STATE (E.G. TITLE XIX PLAN, LEGISLATIVE PRIORITIES, ENTITLEMENT PROGRAMS, ETC.)
- PROVIDE TECHNICAL ASSISTANCE AND RESOURCES TO FEDERAL AGENCIES THAT WILL SENSITIZE THEM TO THE TEMPORARY SUPPORT NEEDS OF FAMILIES WITH SPECIFIC EMPHASIS ON THE IMPACT OF THESE SERVICES ON THE FAMILY UNIT. (E.G. OF THE FAMILY UNIT)
- SUPPORT A MAJOR STUDY FUNDED BY THE FEDERAL GOVERNMENT TO ASSESS THE IMPACT OF FAMILY SUPPORT SERVICES ON THE FAMILY UNIT.

FUNDING

- ASSESS AVAILABILITY OF FUNDS FROM STATE AND FEDERAL SOURCES.
- COMPILE A LIST OF ALL AVAILABLE RESOURCES OF NATIONAL FUNDING.
- SUPPORT A PROJECT THAT PROVIDES TECHNICAL ASSISTANCE AND TRAINING ON WRITING LEGISLATION, POLICIES, GRANTS, AND PROPOSALS.

LEGISLATION

- ADVOCATE FOR DEVELOPMENT OF FEDERAL OR STATE LEGISLATION AND REGULATIONS AND VOLUNTARY STANDARDS TO LICENSE ALL RESPITE PROVIDERS AND PROGRAMS (E.G. HOMES, PARAPROFESSIONALS, ESTABLISHMENT OF WAGE HOUR LAWS TO PROTECT CONSUMER AND PROVIDERS).
- DISSEMINATE MAJOR LEGISLATIVE INFORMATION TO PROGRAMS AND CONSUMERS RECOMMENDATIONS THROUGHOUT THE NATION. (SEE NATIONAL RECOMMENDATIONS - SECTION, COMMUNICATIONS NETWORK.) EDUCATE FEDERAL, STATE, AND LOCAL POLICY MAKERS REGARDING THE FAMILY AND "PREVENTION" AND INTRODUCE LONG-RANGE STRATEGIES OF LEGISLATIVE CHANGES.

MISCELLANEOUS

- IDENTIFY REPRESENTATIVES FROM MAJOR INSURANCE COMPANIES WHO MIGHT DISCUSS FAMILY SUPPORT SERVICES AND COVERAGE NEEDED FOR RESPITE AND FAMILY SUPPORT SYSTEMS (POSSIBLY AT NEXT YEAR'S CONFERENCE).
- TECHNICAL ASSISTANCE AND TRAINING ON WRITING LEGISLATION POLICIES, GRANTS, PROPOSALS AND PROGRAM DEVELOPMENT.

THE OVERALL RATING FOR THE CONFERENCE ITSELF RANGED FROM GOOD TO EXCELLENT. THE EVALUATION FORMS INDICATED THAT SOME PARTICIPANTS WERE DISSATISFIED WITH HOTEL ACCOMMODATIONS, SCHEDULING OF WORKSHOPS, AND THE FACT THAT A FEW SESSIONS WERE DELAYED IN STARTING. HOWEVER, BOTH WRITTEN AND VERBAL FEEDBACK SUGGESTS THAT THE MAJORITY OF PARTICIPANTS WERE PLEASED WITH THE CONFERENCE PRESENTATIONS.

OVERALL CONFERENCE EVALUATION

N=63	POOR	FAIR	ADEQUATE	GOOD	EXCELLENT
ORGANIZATION OF CONFERENCE	1	0	5	27	20
BALANCE OF TIME ALLOCATED FOR DISCUSSION AND PRESENTATION	0	2	12	27	15
CONTRIBUTION TO PARTICIPANTS KNOWLEDGE:					
FORUM	0	4	10	20	17
WORKSHOPS	0	3	9	24	19

EVALUATION RESPONSES INDICATED THAT THERE WAS SUFFICIENT TIME FOR DISCUSSIONS AND PRESENTATIONS. ONE HOUR AND THIRTY MINUTES WAS ALLOCATED FOR EACH WORKSHOP SESSION. IN CERTAIN TRACKS THERE WERE AS MANY AS FOUR PRESENTERS SCHEDULED TO SPEAK. THIS RESTRICTED THE AMOUNT OF TIME FOR EACH SPEAKER CONSIDERABLY. PARTICIPANTS ALSO CITED THAT MORE TIME SHOULD HAVE BEEN PROVIDED FOR INFORMAL DISCUSSION AMONG THEMSELVES AND PROGRAM PRESENTERS. THE CONFERENCE AGENDA/FORMAT HAD ACTIVITIES SCHEDULED THROUGHOUT THE ENTIRE DAY ONLY BREAKING FOR LUNCH AND DINNER. HOWEVER,

MOST PARTICIPANTS FELT THAT THEY HAD AN OPPORTUNITY TO CONTRIBUTE TO BOTH FORUM AND WORKSHOP SESSIONS. THE RAW DATA INDICATED THE FOLLOWING:

ORGANIZATION OF CONFERENCE

ONE PERSON FELT THE ORGANIZATION WAS POOR. ON THE OTHER EXTREME, RATING WERE:

20-EXCELLENT

27-GOOD

5-ADEQUATE

BALANCE OF TIME ALLOCATED FOR DISCUSSION PRESENTATIONS

FIFTEEN PERSONS SELECTED EXCELLENT. MOST OTHER PARTICIPANTS RATED THIS SECTION AS FOLLOWS:

15-EXCELLENT

27-GOOD

12-ADEQUATE

2-FAIR

CONTRIBUTION TO PARTICIPANT'S KNOWLEDGE

(MAJOR FORUMS/WORKSHOP SESSIONS)

MOST PARTICIPANTS SELECTED EXCELLENT OR GOOD FOR THIS ITEM. NUMERICALLY THE DATA SHOWS:

FORUMS	WORKSHOPS
17-EXCELLENT	19-EXCELLENT
20-GOOD	24-GOOD
10-ADEQUATE	9-ADEQUATE
4-FAIR	3-FAIR

COMMUNITY-BASED
RESPITE SERVICE SYSTEMS

SUMMARY OF EVALUATION FORM

I. PARTICIPANT INFORMATION

1. TYPE OF PARTICIPANT (CIRCLE ONE)

PARENT CONSUMER SERVICE PROVIDER OTHER _____

2. NUMBER OF YEARS EXPERIENCE IN RESPITE CARE/FAMILY SUPPORT SYSTEMS

_____

3. SEX: MALE FEMALE

4. NAME OF STATE: _____URBAN _____RURAL _____OTHER

II. OVERALL EVALUATION OF CONFERENCE

PLEASE CIRCLE YOUR RESPONSES TO THE FOLLOWING QUESTIONS.

1. POOR 2. FAIR 3. ADEQUATE 4. GOOD 5. EXCELLENT

A. CONTENT AND ORGANIZATION OF CONFERENCE

1. ORGANIZATION OF CONFERENCE	1	2	3	4	5
2. BALANCE OF TIME ALLOCATED FOR PRESENTATIONS AND DISCUSSION	1	2	3	4	5
3. LENGTH OF OVERALL CONFERENCE	1	2	3	4	5
4. CONTRIBUTION TO MY KNOWLEDGE	1	2	3	4	5
A. MAJOR FORUM SESSIONS	1	2	3	4	5
B. CONCURRENT WORKSHOP TRACKS	1	2	3	4	5

B. ARRANGEMENTS

1. CLARITY AND TIMELINESS OF ANNOUNCEMENTS	1	2	3	4	5
2. HOTEL ACCOMMODATIONS	1	2	3	4	5
3. LUNCHEON AND REFRESHMENTS	1	2	3	4	5

III. WHAT FUTURE TRAINING AND TECHNICAL ASSISTANCE NEEDS DO YOU SEE FOR STATES TO IMPLEMENT PROGRAMS OF RESPITE CARE AND FAMILY SUPPORT SYSTEMS?

IV. PLEASE USE THE REST OF THIS PAGE AND THE BACK IF NECESSARY FOR ANY ADDITIONAL COMMENTS OR SUGGESTIONS YOU MAY HAVE.

THANK YOU FOR YOUR COOPERATION IN FILLING OUT THIS FORM.

RESPITE CARE TASK FORCE

ARONOFF, REMY
WASHINGTON METROPOLITAN COUNCIL
OF GOVERNMENTS
1225 CONNECTICUT AVENUE, NW
WASHINGTON, DC 20036
202-223-6800

BANKS, BUENA VISTA
6903 32ND STREET, NW
WASHINGTON, DC 20014
202-362-4696

CAMPBELL, PAMELA
WASHINGTON EPILEPSY FOUNDATION
815 15TH STREET, NW #706
WASHINGTON, DC 20005
202-638-5229

FISHBACK, HILDA
VOCATIONAL REHABILITATION
3715 FIRST STREET, APT. #1017C
SILVER SPRING, MD 20910
301-576-7249

FROMM, SANDRA
4801 DEXTER TERRACE, NW
WASHINGTON, DC 20007
202-337-5179

GOODMAN, ELIZABETH
2943 MACOMB STREET, NW
WASHINGTON, DC 20008
202-554-1645
(MEMBER OF THE DC DEVELOPMENTAL
DISABILITIES COUNCIL)

LOOP, BERTINE
COMMUNITY ALTERNATIVE SERVICE
SYSTEMS (CASS)
4800 EMILE, ROOM 4022
OMAHA, NEBRASKA 68105
402-541-7717

MCMAHON, JEAN
HOMEMAKERS
7926 JONES BRANCH DRIVE
MCLEAN, VIRGINIA

MIDDLETON, ERNEST
COMMUNITY MEDICINE DEPARTMENT
GEORGETOWN HEALTH CAREERS PROGRAMS
2233 WISCONSIN AVE., NW #535
WASHINGTON, DC 20007

MORTON, PEG
MONTGOMERY COUNTY ASSOCIATION
FOR RETARDED CITIZENS
11212 NORRIS DRIVE
SILVER SPRINGS, MD 20902
301-949-1454

PASCHALL, SAMUEL
319 QUACKENBOS STREET, N.E.
WASHINGTON, D.C. 20011
202-544-4600 x 259
(MEMBER OF THE DC DEVELOPMENTAL DISABILITES
COUNCIL)

CHACKLETON, POLLY
D.C. CITY COUNCIL
DISTRICT BUILDING
14TH & E STREETS, N.W.
WASHINGTON, D.C. 20004
202-724-8056

SHOOB, DEANNA
CHILDCARE ASSISTANCE PROGRAM FOR SPECIAL
CHILDREN, INC. (CAPS)
P.O. BOX 1217
SPRINGFIELD, VA 22151
703-256-2321

TERRY, RAYMOND
DIRECTOR, D.C. DEVELOPMENTAL DIABILITIES
COUNCIL
1329 E STREET, N.W. #1056
WASHINGTON, D.C. 20004
202-727-0569

ZEMAN, ALLEN
GREAT OAKS CENTER
12001 CHERRY HILL ROAD
SILVER SPRING, MD 20902

<u>REPRESENTATIVES FROM THE GEORGETOWN UNIVERSITY CHILD DEVELOPMENT CENTER</u>:

GARRETT, DORIS
DIRECTOR, COMMUNITY SERVICES

MAGRAB, PHYLLIS, DIRECTOR
GEORGETOWN UNIVERSITY CHILD DEVELOPMENT CENTER

PRYOR, STANLEY
PROJECT COORDINATOR

TAYLOR, TAWARA
RESPITE CARE PROJECT COORDINATOR

WILLIAMS, VIRGINIA
ASSOCIATE DIRECTOR, COMMUNITY PLANNING

THE FIRST NATIONAL CONFERENCE ON TEMPORARY
FAMILY SUPPORTS FOR DEVELOPMENTALLY DISABLED PERSONS
CONFERENCE PARTICIPANT LISTING

SUZANNE ALBRIGHT
DIRECTOR, HOME CARE SERVICES
SENIOR WORKERS ACTION PROGRAM
55 WEST STATE STREET
AKRON, OHIO 44308

MARY ANN ALLARD
RESEARCH ASSOCIATE
HUMAN SERVICES RESEARCH INSTITUTE
919 18TH STREET, N.W.
WASHINGTON, D.C. 20006

ALMA ALLEN, SUPERVISOR
HOMEMAKERS HOME HEALTH AIDE SERVICES
410 BATH ROAD
BRISTOL, PA 19007

KATHLEEN ANDERSON, PROJECT DIRECTOR
COMMUNITY SERVICE CENTER
2048 NORTH 5TH
KANSAS CITY, KA 66101

GRACE ANDERSON, DIRECTOR
HOMEMAKER DEPARTMENT -
VISITING NURSE ASSOCIATION
HOMEMAKER SERVICE OF SAN DIEGO
8123 ENGINEER ROAD
SAN DIEGO, CA 92111

VIRGINIA ATTRIDGE, DIRECTOR
HOME AIDES OF CENTRAL NEW YORK
550 MIDTOWN PLAZA - E WATER STREET
SYRACUSE, NY 13210

CHUCK BALLANCE, DIRECTOR
COASTAL HOME RESPITE CARE PROJECT
GLYNN COUNTY MENTAL HEALTH
MENTAL RETARDATION CENTER
1609 NEWCASTLE STREET
BRUNSWICK, GA 31520

JANE BARNA, SOCIAL WORKER
NATIONAL CHILDREN'S CENTER
6200 SECOND STREET, NW
WASHINGTON, D.C. 20011

MARION V. BATES, ADMINISTRATIVE ASST.
WISCONSIN COUNCIL ON DEVELOPMENTAL
DISABILITIES
1 W. WILSON STREET, ROOM 1120C
MADISON, WI 53702

JOHN R. BEDIZ
DEVELOPMENTAL DISABILITIES OFFICE
UAF AT SHRIVER CENTER
200 TRAPELO ROAD
WALTHAM, MA 02154

JIM BELLOR, ASSISTANT ADMINISTRATOR
THE HOSPITAL FOR SICK CHILDREN
1731 BUNKERHILL ROAD
WASHINGTON, D.C. 20017

PEARL BERRIDGE, SOCIAL WORKER
UPPER MIDWEST AMERICAN INDIAN CENTER
1113 W. BROADWAY
MINNEAPOLIS, MN 55411

DAVID A. BERNSTEIN, PROJECT DIRECTOR
MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL
201 WEST PRESTON STREET
BALTIMORE, MD 21201

DAN BIDDICK, SUPERVISOR
AREA RESIDENTIAL CARE
2909 KAUFMAN AVENUE
DUBUQUE, IA 52001

LOIS J. BLACKWELL, PRESIDENT/DIRECTOR
JUDEVINE CENTER/AUTISTIC CHILDREN (JCAC)
8667 OLIVE
ST. LOUIS, MO 63132

WILHELMINA BLANTON, SUPERVISOR
HOMEMAKERS HOME HEALTH AIDE SERVICES
410 BATH ROAD
BRISTOL, PA 19007

WILLIAM J. BOWMAN
CENTRAL IOWA
BOX 384
MARSHALLTOWN, IA

LOUISE BREDDON
440 HOLLY HILL ROAD
UNIVERSITY PARK, MD 20782

SUSAN BRODERICK, RESPITE CARE CASEWORKER
RESPITE CARE, MONTGOMERY COUNTY DEPARTMENT
OF SOCIAL SERVICES
5630 FISHERS LANE
ROCKVILLE, MD 20853

JOHNNIE V. BROOKS, DIRECTOR
ADMINISTRATION FOR PUBLIC SERVICES
TITLE XX, DHEW
330 C STREET, SW
WASHINGTON, D.C. 20201

MARY LEE BROOKSHIRE
GEORGIA COUNCIL ON DEVELOPMENTAL
DISABILITIES
4050 ELMS COURT DRIVE
STONE MOUNTAIN, GA 30083

MARCIA PEARCE BURGDORF, DIRECTOR
DEVELOPMENTAL DIABILITIES LAW PROJECT
UNIVERSITY OF MARYLAND LAW SCHOOL
500 WEST BALTIMORE
BALTIMORE, MD 21201

LOLA BUSENBARRICK, SUPERVISOR
DAY DEVELOPMENTAL TRAINING SERVICES
LOUISIANA OFFICE OF MENTAL RETARDATION
721 GOVERNMENT STREET
BATON ROUGE, LOUISANA 70804

ALBERT CALELLO, EXECUTIVE DIRECTOR
CAMBRIDGE FAMILY & CHILDREN'S SERVICE
99 BISHOP RICHARD ALLEN DRIVE
CAMBRIDGE, MA 02139

PAMELA CAMPBELL
WASHINGTON EPILEPSY FOUNDATION
815 15TH STREET NW #706
WASHINGTON, DC 20005

KAY CAPINO, PEDIATRIC CLINICAL NURSE SPECIALIST
COMMUNITY NURSING & DEVELOPMENTAL PROGRAM
DIVISION OF MENTAL RETARDATION
BIGGS BUILDING
DELAWARE STATE HOSPITAL
NEW CASTLE, DE 19720

MICHAEL CARBONE, DIRECTOR
NEW SERVICES - UNITED CEREBRAL PALSY OF CENTRAL INDIANA
711 MAIDEN CHOICE LANE
CNATONSVILLE, MD 21228

CARY CARON, DIRECTOR
RESPITE SERVICES PROJECT
ARCHDIOCESE OF DENVER
2141 SOUTH ZENOBIA STREET
DENVER, CO 80219

MARY L. CARSTENSEN
RESPITE CARE COORDINATOR
CHARLES COUNTY ASSOCIATION FOR HANDICAPPED & RETARDED CITIZENS (HARC)
P. O. BOX 222
LAPLATA, MD 20646

CAROL CATULLE
RESPITE CARE COORDINATOR
LOUDOUN ASSOCIATION FOR RETARDED CITIZENS
P. O. BOX 243
LEESBURG, VA 22075

ADA CHEUNG
VIRGINIA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL
1005 NINTH STREET OFFICE BUILDING
RICHMOND, VA 23219

MRS. EDNA CLUTZ, EXECUTIVE DIRECTOR
ROCHESTER SOCIETY FOR PREVENTION OF CRUELTY TO CHILDREN
49 S. FITZHUGH STREET
ROCHESTER, NY 14614

ALLEN R. COHEN, DIRECTOR
VIRGINIA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL
1005 NINTH STREET OFFICE BUILDING
RICHMOND, VA 23219

ART COHEN
G.A.I.N
301 WEST PRESTON, SUITE 1304
BALTIMORE, MD 21201

MARY A. COOKE
TEMPO PROJECT, MASSACHUSETTS HOSPITAL SCHOOL FOR HANDICAPPED CHILDREN
RANDOLPH STREET
CANTON, MA 02021

DENIS J. CRAIG, PROGRAM DIRECTOR
RESPITE DEVELOPMENTAL DISABILITIES UNIT
MASS. MENTAL HEALTH CENTER
(MENTAL HEALTH PROGRAMS, INC.)
15 ELKO STREET
BRIGHTON, MA 02135

VELAINE CURLILE, SECRETARY-TREASURER
AREA XXI DEVELOPMENTAL DISABILITIES COUNCIL
R.R. 1
MANNING, IA 51455

MARSHA DAKE, DIRECTOR
PROGRAM DEVELOPMENT
NURSING AND HEALTH PROGRAM
AMERICAN RED CROSS NATIONAL HEADQUARTERS
WASHINGTON, D.C. 20006

FRANK DRUMMOND, DIRECTOR
EXCEPTIONAL CHILD CARE SERVICES, INC. (ECCS, INC.)
1117 N. VISTA STREET
LOS ANGELES, CA 90046

GENE EDGAR, DIRECTOR
RESPITE PROVIDER TRAINING PROJECT
103 MILLER HALL, DQ-12
UNIVERSITY OF WASHINGTON
SEATTLE, WA 98195

WES ERWIN, EXECUTIVE DIRECTOR
COMMUNITY LIVING FOR THE HANDICAPPED, INC.
145 SOUTH 5TH STREET
P. O. BOX 997
ST. CHARLES, MO 63301

ERNEST ESKIN, SUPERVISOR OF SOCIAL WORK
TEMPLE UNIVERSITY - WOODHAVEN CENTER
2900 SOUTHAMPTON ROAD
PHILADELPHIA, PA 19154

MAJORIE FEHRER, RESPITE CARE COORDINATOR
REGION IV FAMILY OUTREACH
703 W. MAIN
BOZEMAN, MT 59715

VICTORIA FINK
PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
79 ELM STREET
HARTFORD, CT 06115

HILDA B. FISHBACK, SUPERVISOR
BRS WARD 4 DEVELOPMENTAL DISABILITIES
DC DHR-SRA, BRS
8715 FIRST AVENUE #1017C
SILVER SPRING, MD 20910

MARY FITZPATRICK
CROTCHED MOUNTAIN REHABILITATION CENTER
GREENFIELD, NH

KAYE FLANAGAN, RESPITE CARE COORDINATOR
HOLY INNOCENTS HOMES CARE SERVICE
P. O. BOX 797
33 SHERMAN STREET
PORTLAND, ME 04104

JACK FLOOD
HOPE COTTAGES, INC.
ANCHORAGE, AK 99567

PATRICIA FORGUITES
ADMINISTRATIVE ASSISTANT
MONTPELIER, VT

KATHERINE FOSSETT
RECORDING SECRETARY AND D.C. COORDINATOR
NATIONAL ASSOCIATION OF PHYSICALLY HANDICAPPED, INC.
(HAPH)-NATION'S CAPITAL CHAPTER
1150 12TH STREET, NW - APT. #712
WASHINGTON, D.C. 20005

SANDRA FROMM
4801 DEXTER TERRACE, NW
WASHINGTON, D.C. 20007

JEAN S. FUGERE
SPECIAL SERVICE ASSISTANT
COMMUNITIZATION PROJECT
DEPARTMENT OF MENTAL HEALTH
REGION I-DDO
P.O. BOX 389
NORTHAMPTON, MA 01060

KARLA GARIS
ARIZONIA TRAINING PROGRAM
TUCSON, AZ

ARTHUR R. GEILSER, CHIEF
DIVISION OF SOCIAL AND RECREATIONAL SERVICES
DEPARTMENT OF PUBLIC WELFARE
OFFICE OF MENTAL RETARDATION
411 HEALTH AND WELFARE BUILDING
HARRISBURG, PA 17120

DENNIS GERBER, COORDINATOR
PROJECT H.E.L.O.
CAMBRIDGE FAMILY & CHILDREN'S SERVICES
99 BISHOP RICHARD ALLEN DRIVE
CAMBRIDGE, MA 02139

NINA S. GOLIAN, RESPITE CARE COORDINATOR
MCARC RESPITE CARE
301 S. BREVARD STREET
CHARLOTTE, NC 28202

ELIZABETH GOODMAN
2948 MACOMB STREET, NW
WASHINGTON, D.C. 20008

BARBARA C. GUNDRY, EXECUTIVE DIRECTOR
SERVICES TO SENIORS OF CALHOUN COUNTY, INC.
182 W. VAN BUREN STREET
BATTLE CREEK, MI 49014

DORIS HAAR
DIRECTOR OF RESEARCH AND DEVELOPMENT
DEVELOPMENTAL DISABILITIES OFFICE
MARY SWEITZER BUILDING
330 C STREET, SW - ROOM 3415
WASHINGTON, D.C. 20201

PEGGY HALPERN, REPRESENTATIVE
HOME SERVICES ASSOCIATION OF ST. PAUL, MINNESOTA
2716 ST. PAUL STREET
BALTIMORE, MD 21218

CHERYL A. HANKS, CASEWORKER
JASPER COUNTY SOCIAL SERVICE AND DEPARTMENT OF PUBLIC WELFARE
119 W. HARRISON
RENSSELAER, IN 47978

D. CARLEY HARBOUR
9015 CAPTAINS ROW
ALEXANDRIA, VA 22308

LESLIE F. HERDEGEN, DIRECTOR
DELAWARE YOUTH FOR HUMAN SERVICES
501 OGLETOWN ROAD
NEWARK, DE 19711

DOLORES HERNANDEZ, RESPITE CARE COORDINATOR
PUEBLO ASSOCIATION FOR REATARDED CITIZENS
P. O. BOX 921
PUEBLO, CO 81002

CATHERINE HIGGINS
COORDINATOR OF SPECIAL PROJECTS
EASTER SEAL SOCIETY
901 DEWEY AVENUE
HAGERSTOWN, MD 21740

MARY HILL, ADMINISTRATOR
FAMILY CARE CONTRACT
VISITING NURSE ASSOCIATION OF DALLAS
4606 GREENVILLE AVENUE
DALLAS, TX 72506

BILL HILLMAN
BUREAU OF EDUCATION OF THE HANDICAPPED (BEH), DHEW
DIVISION OF PERSONNEL PREPARATION
DONAHOE BUILDING
400 MARYLAND AVENUE, SW
WASHINGTON, D.C. 20202

DONNA DALEY HINKLE
ASSOCIATE DIRECTOR
SYSTEMS UNLIMITED, INC.
1020 WILLIAM STREET
IOWA CITY, IA 52240

ELIZABETH HORMANN, WRITER/EDITOR
AMERICAN INSTITUTE OF RESEARCH
THE SINGLE PARENT
7 HENRY STREET
BELMONT, MA 02178

BARBARA HOUGH, ADMINISTRATOR
HOME AID RESOURCES PROGRAM
BUREAU OF DEVELOPMENTAL DISABILITIES
M.S. 421
OLYMPIA, WA 98504

SUSAN S. HOWARD, DIRECTOR
RESPITE HOME
204 N. KERR AVENUE
WILMINGTON, NC 28401

CAROLYN HUDSON
RESPITE CARE COORDINATOR
RESPITE CARE SERVICES FOR THE HANDICAPPED
CENTRAL MARYLAND REGIONAL DIRECTION CENTER
COUNTY ADMINISTRATION BUILDING
ROOM 1126
UPPER MARLBORO, MD 20870

INEITHA HUNDER, ASSISTANT DIRECTOR
CENTER FOR EXCEPTIONAL CHILDREN
85 E. NEWTON STREET
BOSTON, MA 02118

SISTER MARY PAUL PANCHILL, CONSULTANT
SOCIAL SERVICES
NEW YORK STATE DEPARTMENT OF MENTAL HYGIENE
ROOM 56-57, TWO WORLD TRADE CENTER
NEW YORK, NY 10047

CAROLE JENNE, COORDINATOR
HOMEMAKER SERVICE
MONROE COUNTY OPPORTUNITY PROGRAM
942 E. FIRST STREET
MONROE, MI 48161

ELAINE JOYCE, PROJECT COORDINATOR
FAMILY EDUCATION PROJECT
KENNEDY FOUNDATION
3520 PROSPECT STREET, NW
WASHINGTON, D.C. 20007

JOSEPH J. KENNAN, JR.
DIVISON OF RETARDATION
WEST WARRICK, RI 02893

MAGGIE KENNEY
ENCOR
885 SOUTH 72ND
OMAHA, NE 68114

JEFF KIELSON
REGIONAL MENTAL RETARDATION DIRECTOR
MASSACHUSETTS DEPARTMENT OF MENTAL HEALTH
LINDEMAN MENTAL HEALTH CENTER
GOVERNMENT CENTER
BOSTON, MA

SHEILA KINGSTON
DD PROJECT - STATE OF MINNESOTA
PATTEE HALL
150 PILLSBURY DRIVE, SE
MINNEAPOLIS, MN 55455

RANDY KITCH, KANSAS COORDINATOR
PEOPLE FIRST
816 LANE
TOPEKA, KS

ALMA P. KITCHEN, PROGRAM COORDINATOR
DEVELOPMENTAL DISABILITIES ADVOCACY NETWORK, INC.
1611 CITY TOWERS
301 CHESTNUT STREET
HARRISBURG, PA 17101

FRANK MILLET
HOPE COTTAGES, INC.
2805 BERING STREET
ANCHORAGE, AK 99567

BARRY MINTSER, LEGAL CONSULTANT
MASSACHUSETTS RESPITE CARE POLICY DEVELOPMENT PROJECT
110 TREMONT STREET - 6TH FLOOR
BOSTON, MA 01208

MIDGE MINTUN, ADMINISTRATIVE SUPERVISOR
KANSAS CHILDREN'S SERVICE LEAGUE
TOPEKA DISTRICT
RESPITE/FAMILY CARE PROJECT
P. O. BOX 5314
TOPEKA, KS 66605

PEG MORTON
MONTGOMERY COUNTY ASSOCIATION FOR RETARDED CITIZENS
11212 NORRIS DRIVE
SILVER SPRING, MD 20902

MARIA ZOE MOSSAIDES, LEGAL COUNSEL
COMMONWEALTH OF MASSACHUSETTS DEVELOPMENTAL DISABILITIES PLANNING UNIT
540 THE STATE HOUSE
BOSTON, MA 02130

THELMA MULLIN, SOCIAL WORKER
D.C. SOCIETY FOR CRIPPLED CHILDREN
2800 13TH STREET, N.W.
WASHINGTON, D.C. 20009

ROBERT MURRAY, DIRECTOR
REGIONAL RESPITE BOSTON CHILDREN'S SERVICE
867 BOYLSTON STREET
BOSTON, MA 02116

LEROY M. NASH, RESEARCH DIRECTOR
ROCHESTER AREA MULTIPLE SCLEROSIS
1000 ELMWOOD AVENUE
ROCHESTER, NY 14620

JOHN J. NOONE, CONSULTANT
HAWKINS AND ASSOCIATES
1005 PACA LANE
ANNAPOLIS, MD 21403

GRATIA KOCH, COORDINATOR
F.A.C.T. PROJECT
SYSTEMS UNLIMITED
1020 WILLIAM STREET
IOWA CITY, IA 52240

LEE KOENIGSBURG, CONSULTANT
EMC INSTITUTE
24 MAPLEWOOD MALL
PHILADELPHIA, PA 19144

GEORGEO K. KUBICA, PROJECT DIRECTOR
DAUPHIN RESIDENCES, INC.
1 NORTH PROGRESS AVENUE
HARRISBURG, PA 17109

KAREN LAWRENCE
MENTAL RETARDATION COORDINATOR
LOUDOUN COUNTY MH/MR SERVICES BOARD
1 E. MARKET STREET
LEESBURG, VA 22075

EMILY LAYZER, STAFF ASSOCIATE
NATIONAL COUNCIL FOR HOMEMAKER-
HOME HEALTH AIDE SERVICES
67 IRVING PLACE
NEW YORK, NY 10003

KATHLEEN D. LIVELY, DIRECTOR
MENTAL RETARDATION PROGRAM
APPALACHIAN MENTAL HEALTH CENTER
P. O. BOX 1170
ELKINS, WV 26241

ELIZABETH LODEN, SCHOOL SOCIAL WORKER
NATIONAL CHILDREN'S CENTER, INC.
6200 SECOND STREET, NW
WASHINGTON, D.C. 20011

CYNTHIA LOVE, COORDINATOR OF RESPITE CARE
RESPITE CARE, MONTGOMERY COUNTY DEPARTMENT OF SOCIAL SERVICES
5360 FISHERS LANE
ROCKVILLE, MD 20853

JOANNA E. MCCABE, DIRECTOR
NURSING AND COTTAGE LIFE
DIVISION OF MENTAL RETARDATION
ROUTE 1, BOX 1000
GEORGETOWN, DE 19947

DIANE MCGEE
ROUTE #1, BOX 431-A
FOUR OAKS, NC

MAIANNE SMITH, RESPITE COORDINATOR
COMMUNITY NURSING AND DEVELOPMENTAL PROGRAM
DIVISION OF MENTAL RETARDATION
ROUTE 1, BOX 1000
GEORGETOWN, DE 19947

MARY LOU SMITH, AREA ADMINISTRATOR
CHILD & FAMILY SERVICES - HOMEMAKER DEPARTMENT
234 SOUTH WABASH
CHICAGO, IL 60604

PATTY SMITH, REGIONAL COORDINATOR
PILOT PARENT PROGRAM
GREATER OMAHA ASSOCIATION FOR RETARDED CITIZENS (GOARC)
3212 DODGE
OMAHA, NE 68131

KIM SNYDER, DEVELOPMENTAL THERAPIST
PROJECT H.E.L.O.
CAMBRIDGE FAMILY & CHILDREN'S SERVICES
99 BISHOP RICHARD ALLEN DRIVE
CAMBRIDGE, MA 02139

PATRICIA SORENSEN
COMPREHENSIVE DEVELOPMENTAL CENTERS, INC.
900 WEST NORWAY ROAD
BOX 40
MONTICELLO, IN 47960

WILLIAM H. STALEY, JR., DIRECTOR
SOUTH MISSISSIPPI RETARDATION CENTER
P. O. DRAWER 530
LONG BEACH, MS 39560

JEAN L. TATES, RESPITE COORDINATOR
CENTER FOR EXCEPTIONAL CITIZENS
85 EAST NEWTON STREET
BOSTON, MA 02118

TED TAYLOR, DEPUTY DIRECTOR
ACCREDITATION COUNCIL/MR-DD
JOINT COMMISSION ON ACCREDITATION OF HOSPITALS
875 NORTH MICHIGAN AVENUE
CHICAGO, IL 60611

RAYMOND TERRY, DIRECTOR
D. C. DEVELOPMENTAL DISABILITIES COUNCIL
1329 E STREET, NW - #1056
WASHINGTON, D.C. 20004

GLADYS C. O'LEARY
MAYDAY MISSOURI ASSOCIATION FOR AUTISTIC CITIZENS
11170 PATRIN COURT
ST. LOUIS, MO 63126

JOHN PARRY, EXECUTIVE DIRECTOR
MARYLAND ADVOCACY UNIT FOR THE DEVELOPMENTALLY DISABLED
301 W. PRESTON STREET - ROOM 1304
BALTIMORE, MD

DR. SAMUEL PASCHALL
319 QUACKENBOS STREET, NE
WASHINGTON, D.C. 20011

EVELYN C. PAUL, PROGRAM MANAGER
HENNEPIN COUNTY COMMUNITY SERVICES DEPARTMENT
A-13 GOVERNMENT CENTER
300 SOUTH SIXTH STREET
MINNEAPOLIS, MN 55487

MS. VIOLA PEOPLES, HOMEMAKER SUPV.
CHILDREN'S AID SOCIETY
3600 8TH AVENUE, SOUTH - SUITE 300
BIRMINGHAM, AL 35222

SANDRA L. POTTS, HOMEMAKER SUPV.
FAMILY SERVICE ASSOCIATION OF
BROWN COUNTY
1546 DOUSMAN STREET
GREENBAY, WI 54303

JACQUELYN B. REED
RESPITE CARE COORDINATOR
ALAMANCE-CASWELL AREA MENTAL HEALTH
CENTER
1946 MARTIN STREET
BURLINGTON, NC 27215

MILTON W. ROBERTS, EXECUTIVE DIRECTOR
GREATER KANSAS CITY FOUNDATION FOR
RETARDED CHILDREN
1014 W. 39TH STREET
KANSAS CITY, MO 64111

BETSY ROGERS
WORCESTER AREA ASSOCIATION FOR
RETARDED CHILDREN
50 FRANKLIN STREET
WORCESTER, MA 01508

ALFREDO ROTUNDO, DIRECTOR
REHABILITATIVE SERVICES ADMINISTRA-
TION (RSA)
DHEW - OFFICE OF FINANCIAL OPERATION
300 C STREET, SW
WASHINGTON, D.C. 20201

CHARLES C. MCGOLDRICK, JR.,
OUTREACH AND PROJECTS COORDINATOR
CROTCHED MOUNTAIN REHABILITATION
CENTER
GREENFIELD, NH 03047

E. MCGRATH, COMPTROLLER
VISITING HOMEMAKER-HOME HEALTH AIDE
SERVICE OF BURLINGTON COUNTY
ROUTE 38
MOUNT HOLLY, NJ 08060

JEAN MCMAHON, ZONE STAFF SPECIALIST
HOMEMAKERS UPJOHN
7926 JONES BRANCH DRIVE
MCLEAN, VA 22101

PAT MCMAHON, PROJECT DIRECTOR
ESPERANZA PARA NUESTRAS NINOS
1830 VALDORA, S.W.
P. O. BOX 12212
ALBUQUERQUE, NM 87105

MARTHA MANY GREY HORSE
MOUNTAIN PLANS CENTER FOR SERVICES
TO HANDICAPPED CHILDREN
DENVER, CO

JOHN L. MARKS, JR., ASSISTANT DIRECTOR
WEST VIRGINIA ADVOCATES FOR THE DEVELOP-
MENTALLY DISABLED
SUITE 411, 1021 QUARRIER STREET
CHARLESTON, WV 25301

MARY JIM MARTIN, DIRECTOR
SOCIAL SERVICES AND RESPITE SERVICE PROJECT
SAN DIEGO ASSOCIATION FOR RETARDED CITIZENS
3035 G STREET
SAN DIEGO, CA 92102

ERNEST MIDDLETON
COMMUNITY MEDICINE DEPARTMENT
GEORGETOWN HEALTH CAREERS PROGRAM
2233 WISCONSIN AVENUE, NW #535
WASHINGTON, D.C. 20007

LOUISE MILES, CHAIRMAN
ADVISORY BOARD - HOMEMAKER SERVICE
MONROE COUNTY OPPORTUNITY PROGRAM
942 E. FIRST STREET
MONROE, MI 48161

BEVERLY SANDERS, PH.D.
MENTAL HEALTH COORDINATOR
ALAMANCE-CASWELL AREA MENTAL HEALTH CENTER
1946 MARTIN STREET
BURLINGTON, NC 27215

K. SCHIMMEL, EXECUTIVE DIRECTOR
VISITING HOMEMAKER-HOME HEALTH AIDE SERVICE
OF BURLINGTON COUNTY
ROUTE 38
MOUNT HOLLY, NJ 08060

JOYCE SCHNELL, SOCIAL WORKER
VISITING HOMEMAKERS & HOME HEALTH AIDES
OF GLOUCESTER
116 NORTH BROAD STREET
WOODBURY, NJ 08096

ABBY SEEMANN, PROGRAM COORDINATOR
TRI-COUNTY RESPITE CARE PROGRAM
P. O. BOX 5071
ALOHA, OR 97005

IRENE C. SHEA, RESPITE CARE COORDINATOR
WORCESTER AREA ASSOCIATION FOR RETARDED
CHILDREN
50 FRANKLIN STREET
WORCESTER, MA 01530

DEANNA SHOOB
CHILDCARE ASSISTANCE PROGRAM FOR SPECIAL
CHILDREN, INC. (CAPS)
P. O. BOX 1217
SPRINGFIELD, VA 22151

JUDITH A. SHUMWAY, CASE MANAGER/CLIENT
SERVICES COORDINATOR
HENRICO COUNTY MENTAL HEALTH/MENTAL
RETARDATION SERVICES BOARD
8730 LANDMARK ROAD
RICHMOND, VA 23228

BEN SKINKER, COMMUNITY FACILITATOR
CHARLES CITY COMMUNITY FACILITATION
PROGRAM FOR DEVELOPMENTALLY
DISABLED
BOX #6
CHARLES CITY, VA 20303

HELEN SMIDDY, COORDINATOR
COMMUNITY NURSING AND DEVELOPMENTAL
PROGRAM
DIVISION OF MENTAL RETARDATION
BIGGS BUILDING
DELAWARE STATE HOSPITAL
NEW CASTLE, DE 19720

LINDA C. VELDHEER
VIRGINIA DEPARTMENT OF MENTAL HEALTH
AND MENTAL RETARDATION
DEVELOPMENTALLY DISABLED UNIT
RICHMOND, VA 23225

DON WILKINS
LOUISIANA DEVELOPMENTAL DISABILITIES
COUNCIL
LOUISIANA STATE UNIVERSITY
BATON ROUGE, LA

SUSAN G. WILKINSON, CASEWORKER
RESPITE CARE - ST. MARY'S COUNTY
DEPARTMENT OF SOCIAL SERVICES
BOX 317
LEONARDTOWN, MD 20650

MARILYN WILSON, DIRECTOR ADULT
SERVICES/RESPITE COORDINATOR
SHORT/LONG TERM RESIDENTIAL CARE
59 CAROTHERS ROAD
NEWPORT, KY 41071

MAUREEN WINN, LEGISLATIVE CHAIRPERSON
COUNCIL OF THE HANDICAPPED
10 WEST CHARDON
WINCHSTER, MA

JOSEPH A. WITT, JR., SOCIAL WORKER
ELIZABETH LEVINSON CENTER
159 HOGAN ROAD
BANGOR, ME 04401

ELOISE WOLF, DIRECTOR
BARRY COUNTY COMMISSION ON AGING
120 NORTH MICHIGAN
HASTINGS, MI 49058

PATRICIA ZANELLA, ADMINISTRATOR
COMMUNITY SERVICES DIVISION OF
RETARDATION
DEPARTMENT OF MHRH, STATE OF
RHODE ISLAND
600 NEW LONDON AVENUE
CRANSTON, RI 02920

JOHN ZARECK
DEPARTMENT OF MENTAL HEALTH
BROCKTON, MA

DR. ALLEN L. ZEMON
GREAT OAKS CENTER
12001 CHERRY HILL ROAD
SILVER SPRING, MD 20904

GEORGETOWN UNIVERSITY CHILD DEVELOPMENT
CENTER PARTICIPANTS
GEORGETOWN CHILD DEVELOPMENT CENTER
3800 RESERVOIR ROAD, N.W.
BLES BLDG., ROOM CG-52
WASHINGTON, D.C. 20007
(202) 625-2051

JENNIE AUSTIN
LYNN BALZER-MARTIN
ELAINE BLYLER
B. PATRICK COX
GEORGIA DEGANGI
JEAN FARLEY
JACKIE FEINER
MARYELLEN FERGUSON
JAN FISKE
DEBRA FOLBERG
LYNNE FOLTZ
DORIS GARRETT
ELLIOT GERSH
JANE KARKALITS
TOM LINSCHEID
PHYLLIS MAGRAB
JEAN MURPHY
JUDY OLIVER
GAIL PERRY
STANLEY PRYOR
NINA SCRIBANA
NANCY STRIFFLER
TAWARA TAYLOR
VIRGINIA WILLIAMS
SHARON WILLIG

THE CENTER FOR THE DEVELOPMENT OF COMMUNITY
ALTERNATIVE SERVICE SYSTEMS PARTICIPANTS
MEYERS CHILDREN'S REHABILITATION INSTITUTE
UNIVERSITY OF NEBRASKA MEDICAL CENTER
OMAHA, NE 68105
(402) 541-7717

E. WADE HITZING
MARK KILLENBECK
BERTINE LOOP
KATHLEEN ROSS

Afterword

There continues to be an immediate and urgent need to develop a national strategy for supporting families. There does seem to be an increasing trend to the family unit across the country to focus on and recognize its role in shaping the larger community environment. However, most of the issues identified by the Conference participants have not been resolved.

There is still no community, region, or state today that has put into place the four major cornerstones of a community-based system of family resources services.

There is still a need for a National Family Resource Coalition for Family Support Services that will -

- refer agencies and persons to other members for resources, information exchanges and consultation.
- form key linkages between the Coalition and federal, state and local officials (who ultimately control program development through manipulation of funding and resource supports).
- identify, review and disseminate resource materials and update members on trends and developments.
- support and maintain communication resource networks and directories.
- provide or locate appropriate training and technical assistance to communities implementing projects.

- secure and mobilize resource persons for program evaluation and legislative/funding development.
- organize active lobby and advocacy efforts on behalf of the Coalition and other interest groups supporting community-based family resource programs.

A few states, (notably California, Iowa, Louisiana, Massachusetts, Nebraska, Pennsylvania, and Washington) have begun to commit planning and service funding towards developing more comprehensive services in this area. Federal committment through support and participation in this vital effect has not been realized.

There are still too many communities, regions and states where funding competition and program isolation that ultimately casues the re-invention of the wheel and the waste of the consumer's precious time and money.

They are forced to accept rigid and unresponsive programs that are not what they want or need. There is still no comprehensive system planned or operating that recognizes that the supports and resources needed by any family changes with the family's own growth.

Starting and supporting the community-based respite programs and family support systems is a long-neglected challenge. Like most good things, it takes even harder work to continue "soft" programs that are usually poorly funded and on the fringe of the community mainstream.

The First National Conference on Temporary Family Supports and Integrated Respite Services Systems brought together a group of people who shared many of their own personal experiences and insights (as well as "hindsights"

These participants (including the presenters) represented a wide variety of family support systems. They were involved in programs that represented many kinds of geographic locations and cultural differences.

Perhaps the major contribution of the Conference was its role in providing a forum for this informal communication network to develop.

Since the date of the Conference, many of the participants have continued to exchange resources and share their knowledge. Their committment to quality consumer-centered services has been reflected in their cooperative support.

This report has been delayed due to lack of financial support and bureaucratic mazes. In spite of the obstacles, the report contains information about vital programs and people that are struggling to reflect the resources, as well as the needs of the families they serve.

The responsibility of developing creative programs in spite of funding "limitations" is dependent, finally, on our own attitudes and perceptions.

It is a responsibility that must be equally shared by community programs with the consumers who will use them and financially support them with their presence in the programs.

We will continue our efforts to support a National Coalition for Families. Finally, we hope that this First National Conference on Temporary Family Supports and Integrated Respite Services was reflective of a need for immediate redirection of policy priorities and funding patterns.

Bertine Loop
Omaha, Nebraska
December, 1979

APPENDIX

RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: April 26, 1978 Interviewer: _____

Name of Agency: Greater Omaha Association for Retarded Citizens

Street: 3212 Dodge Street

City: Omaha State: Nebraska Zip: 68131

Program Contact: Patty Smith - Pilot Parent Program

Title: Coordinator Telephone: (402) 348-9220

Applied Definition for Respite: Whoever and whatever a parent needs and when they need it.

Part A: Demographics of Agency which is Sponsoring/Governing the Respite Program/Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Douglas and Sarpy Counties - 520,000 Pop.

1.2 Total population agency serves (e.g., general populace; special segment) 4,350

1.3 Age range of persons served all ages

1.4 Disabilities of persons served (primary, secondary and other) Mental Retardation, Epilepsy, Cerebral Palsy, Autism, hearing impaired, and visually impaired, emotionally disturbed, and learning disabled.

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped _____

N/A

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? N/A

1.6 Percentage of those who require more than average (of popluation served) amount of training/care _____

What is the amount of staff time needed to provide this? N/A

1.7 Percentage non-ambulatory 10%

2.0 Types of service offered through agency Parent support, public education, advocacy, youth activities, information and referral.

3.0 Sources of referral to agency Medical community, Visiting Nurse Association, General membership, current clients, Schools, churches, and ENCOR.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Board of Directors; 22 committees

4.2 State and local regulations, guidelines, standards, zoning N/A

4.3 Current, pending, and future legislation N/A

5.0 Funding sources (percentage if known)

5.1 Federal 36%

5.2 State 6%

5.3 Local 58%

5.4 Other

6.0 Agency's strengths/areas of excellence (Explain/Describe) Innovative and creative programming.

'.0 Agency's limitations/areas requiring improvement Funding stability

'rt B: Respite Program/Services

..0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) The Pilot Parent Program is one in which experienced parents of mentally retarded children are matched with parents of new born, newly diagnosed, or recently acknowledged retarded children so that various forms of support can be provided to these "new" parents. This program was initiated in 1971 and became operational in February, 1972. Pilot Parents helps to provide emotional support, furnish general facts and information about mental retardation, cerebral palsy, epilepsy, and autism, transmit specific information regarding parent movement, professional services, and programs available, and provide intorductions to other parents of handicapped children.

1.2 Where services are provided

A. In-home X

B. Out-of-home X

C. Institutional setting X

D. Other Telephone contacts

1.3 Means of delivery Parent to parent

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 2,850

2.2 Age range All ages.

2.3 Disabilities of person served Mental retardation, cerebral palsy, epilepsy, autism

2.4 Percentage age:

A. 0 - 5 287

B. 5 - 18 120

C. 19 - 29 80

D. 30 - 55 19

E. 55 and over 1

2.5 Percentage of severe/profound (multi-handicapped) Estimate - 35% during this last year.

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? Someone who needs a great deal of help.

3.6 Persons who need intensive or specialized training/care All of our children do.

Explain what is meant by those "who need intensive or specialized training/care" 100%

2.7 Percentage non-ambulatory

.0 Recruitment of Respite Program staff

3.1 Target group Parents of children with mental retardation, epilepsy, cerebral palsy and autism.

3.2 Method Request names of potential candidates from the GOARC Board, Nebraska Epilepsy League, United Cerebral Palsy, from counselors at ENCOR, Chairpersons of various parent groups, from day care centers, and from Pilot Parents themselves.

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3.3 Recruitment materials, tools used/developed The GOARC Gazette (newsletter), and publications in other organizations.

.0 Training of Respite Program staff

4.1 Target group Perspective pilot parents.

4.2 Method An eight-week training session.

4.3 Curriculum Pilot Parenting, mental retardation, epilepsy, cerebral palsy, and autism. Normalization, community services, psychiatrist view of pilot parenting, and infant stimulation.

4.4 Training materials; tools used/developed Films, publications, brochures and speakers with expertise in the various segments of the curriculum.

4.5 Source of funding Federal grant.

.0 Community Development

5.1 Media resources Mass media, radio spots, TV appearances, stories in newspapers, speaking engagements throughout the community.

5.2 Parent education Pilot Parent meetings, information in GOARC newsletter, film strip about Pilot Parents.

5.3 Agency education Contacts with agencies through speaking engagements and distribution of brochures that tell of the Pilot Parent Program.

5.4 Community education Radio spots, TV appearances, stories in newspapers, speaking engagements throughout the community, involvement in education of universities, colleges, high school, and relgion classes, involvement in workships, conventions, seminars for parents and professionals.

5.5 Materials; tools used/developed File "Growing Together" on pilot parenting, film "Cry Sorrow, Cry Hope" and brochures, posters, packets of materials, including physicians packets, hospital packets, training packets, new parent packets.

5.0 Administration

6.1 Criteria for eligibility of respite services Being the parent of a child with handicapping conditions.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided

As long as needed.

6.3 Methods of referral to program Pilot Parents, GOARC members, hospitals, schools, churches, and other community service agencies, friends, relatives, and interested citizens in the community.

6.4 Method of referral to service providers Telephone calls, letters, person-to-person. Referrals are made to the Pilot Parent Program. We accept the responsibility for contacting the "new" parent in need.

6.5 Cost of service to client/fees charged by agency/sliding scale None

6.6 Cost of service to agency (operating, indirect, capital costs)

6.7 System of payment (broker, voucher, direct, to service provider, etc.) None

6.8 Provisions for transportation N/A

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Project director, Regional coordinator, Staff, COARC Board of Directors, Pilot Parent Advisory Committee, and Regional Advisory Committee.

7.2 State and local regulations, standards, guidelines, zoning N/A

7.5 Current, pending, and future legislation N/A

3.0 Respite staff/personnel

8.1 Total number staff 4 paid staff (includes one secretary), 50 volunteers.

8.2a Number supervisory staff/administrator 1

8.2b Professional expertise, special training or skills, relevant experience, etc. Three of staff are parents of handicapped children who have expertise in dealing with other parents and parent groups and who have knowledge of resources within the community.

8.3a Number direct service staff Four paid staff with 50 volunteer families.

8.3b Professional expertise, special training or skills, relevant experience, etc. All Pilot Parents have received training and have been screened to determine their own adjustments and their ability to relate to help other parents.

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.)

8.4b Professional expertise, special training or skills, relevant experience, etc. Staff has background of formal and informal training. Staff development includes Normalization training, ENCOR orientation, Pilot Parent Training, Assertiveness training and other counseling opportunities, i.e., P.E.T.

8.5 Staffing patterns/system for scheduling direct services staff Families are matched as closely as possible according to the functional level of the handicapped child, the cause of the handicap or secondary handicap, age of parents, age of child and family structure. There are also other considerations.

.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) 90%

B. State

C. Local 10%

9.2 Client direct payment N/A

9.3 Donations All are accepted.

9.4 Other

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) Pilot parents, neighborhood cities, religious nurturing groups, Greater Omaha Youth Association for Retarded Citizens, other self help groups.

10.2 Agencies (supportive, ancillary, generic) Easter Seals, ChildFind, Nebraska Psychiatric Institute, Boystown Institute, United Cerebral Palsy, Epilepsy League of Nebarska, National Association for Autistic Children, Myer Childrens' Rehabilitation Institute, Visiting Nurse Association, Eastern Nebraska Community Office of Retardation, Operation Comfort.

10.3 Materials/Tools Toy Lending Library, Nebraska Psychiatric Institute, Myer Children's Rehabilitation Institute, GOARC parent library.

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.) and Special training, persons with autism, persons to work with severely profoundly handicapped children.

11.2 Agencies (supportive, ancillary, generic) Good respite services. A more comprehensive group of respite help. More counseling opportunities for parents. Help with financial needs of families.

11.3 Materials/Tools Loan of movies, assistance with producing training films for parents. Assistance with respite weekends for parents - i.e., rest and relaxation and training.

12.0 Strengths/strong points of Respite program Involvement of the fathers and other family members. A complete system to find the "new" parent when the needs are most intense. Can be operated as a completely volunteer organization. Special interest groups.

13.0 Identified weaknesses/limitations of respite program Sometimes not enough follow along after initial intervention. Not enough time to do all the things we want to do for families.

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Evaluation/Accountability

14.1 Internal Annual audit and ongoing staff evaluation. Program evaluations and accountability on a quarterly basis to funding source.

14.2 External Plan is being implemented to have an outside evaluation of program during this grant year.

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CENTER FOR THE DEVELOPMENT OF

COMMUNITY ALTERNATIVE SERVICE SYSTEMS

Date: January 27, 1977

Interviewer: Dianne E. Smith

Name of Agency: The Visiting Nurse Association of Dallas

Street: 4606 Greenville Avenue

City: Dallas State: Texas Zip: 75206

Program Contact: Ms. Mary Hill

Title: Family Care Contract Administrator Telephone with area code: 214-369-5500

Applied Definition for Respite: Home based health care as alternative to institutionalization

Agency Decmographics

Population

City: County: circa one million Region

State: Service Area: cities of Dallas, Plano and Kaufman Counties

Agency: 3000

Age Range: birth to death

Disabilities: all

%Severe/Profound/Multiple Disabilities: 75% -- total care

Service

Types of Agency: voluntary, non-profit

Services Offered: nursing, home management service, therapy service, nutrition service, personal care organization

Agency Competencies: only area/community comprehensive health care agency

Source of Referral: anyone

Respite Program Demographics

Number of Persons served: 1400

Age Range: 18 years and up

Disabilities: SSI definition (10% are DD)

Number of Staff: 1428 Direct Service Staff: 1400

Support Staff: 1 administrator, 3 coordinators, 24 supervisors

Staffing Patterns: 1 provider per client (up to 3 clients per provider)
58 provider/clients per supervisor

Parents, Volunteers, Students:

Criteria for Admission: current SSI recipient

Duration: follows funding mechanism - need justified every 6 months

Program Components: (Brief Description) Hygienic Assistance-Client able to participate, Household Assistance-Maintainance of sanitary environment, Escort Service-Only on public transportation, Companionship-Physical Supervision

Parent Training:

Staff Training: none - plans to train 200 providers for 120 hours

Community Training: only through PR and PE Dept of VNA

In-Home:

Out of Home:

Team Approach: VNA,DPW are assessment/assistance team

Management System:

Crisis Intervention (Catastrophic and Emergency):

Parent Relief:

Training Limitations:

Training Patterns:

Training Programs: A contract between Dallas Women's University, El Centro College, Office of Continuing Education and VNA for $46,000 will develop and provide 120 hours of training to 200 providers. This a (over)

Evaluation: Once a month the supervisor does a Family Care Worker Evaluation/Every 6 months the provider/client contract is reviewed-service/cost effectiveness.

Source of Referral: VNA

Describe Program Setting: in client's home

Funding Patterns: VNA pays the providers $2.30/hour; charges Dept of Public Welfare actual cost (approximately $3.14/hour) DPW used Title XX funds

Cost Analysis:

Materials and Tools Developed; used: as of July 1, 1977; the training packet should be available

Identified Resources:

Potential Resources: Use of formula being developed in order to establish an equitable funding level; training model

Respite Competencies: Some forms for documentation; supervisors' proficiency; total in-home program; low cost; use of relatives and and friends as providers

Needs: Training; understanding between VNA/DPW according to needs versus funding

Future Needs:

Limitations: Low reimbursement levels; only SSI adult recipients eligible

RESPITE SERVICES CONCEPT DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: April 28, 1978 Interviewer: Barbara A. Hough (completed form)

Name of Agency: BUREAU OF DEVELOPMENTAL DISABILITIES

Street: Mail Stop: OB 42C

City: Olympia State: Washington Zip: 98504

Program Contact: BARBARA A. HOUGH

Title: ADMINISTRATOR, HOME AID RESOURCES PROGRAM Telephone: 206 - 753 - 1447

Applied Definition for Respite: Direct services to individuals who are developmentally disabled and their families when and where no other state, community or private services exist or, such services are found to be inappropriate to meet the needs of the individual; prevent inappropriate institutionalization and decrease the need for continuing institutionalization; strengthen the family as a primary resource; stabilize or develop a preferred living situation; increase the individual's independence.

Part A: Demographics of Agency which is Sponsoring/Governing the Respite Program/Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) entire state (39 counties)

1.2 Total population agency serves (e.g., general populace,[1] special segment[2]) 3,661,975[1] 7,705[2] (3-78)

Note: [2] = Case Services Client Population as of March, 1978

1.3 Age range of persons served All ages

1.4 Disabilities of persons served (primary, secondary and other) Mental Retardation, Cerebral Palsy, Epilepsy, Autism, Auditorily Impaired, Visually Impaired, other Neurological Impairments

59

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1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped

Approximately 18% (AAMD)

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? AAMD Note: See attached Bureau Policy Directive 505 and Guidelines For Bureau Policy Directive 505

1.6 Percentage of those who require more than average (of popluation served) amount of training/care 7% Home Aid*

What is the amount of staff time needed to provide this? 952 hours = .07% of total (3mo.period*)

1.7 Percentage non-ambulatory This information is not collected for Home Aid Resources Program Data..

2.0 Types of service offered through agency Information, Referral, Placement, Assessment, Counseling, Resource

(over)

3.0 Sources of referral to agency Comm. Agencies, State Offices, D.D.Boards, Individuals, Institutions

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Citizen input to program planning; DDPC; Bureau Policy Advisory Group

4.2 State and local regulations, guidelines, standards, zoning Revised Codes of Washington (RCW); Washington Administrative Codes (WAC); Bureau Policies; Program Policies and Guidelines

4.3 Current, pending, and future legislation No new legislation for Home Aid Resources Program

5.0 Funding sources (percentage if known)

5.1 Federal 69% Federal Monies

5.2 State 31% State

5.3 Local N/A

5.4 Other N/A

6.0 Agency's strengths/areas of excellence (Explain/Describe) Local office locations and staffing; Specialized Staff; Specialized Bureau programs and services

61

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7.0 Agency's limitations/areas requiring improvement Staffing ratio is low. Increases require additional legislation and funding.

Part B: Respite Program/Services

1.0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) Legislature appropriated $760,000 to implement Home Aid Resources Program in the 1975-1977 biennium. Development of program policies, operational manual and WAC's from July to Jan. Implementation in Jan. 1976. 1977 -1979 biennium appropriation in $1,010,000. (See Attached Program Policies)

1.2 Where services are provided

A. In-home client, family, guardian or surrogate family home

B. Out-of-home service provider home, therapy facility

C. Institutional setting none

D. Other community facilities (recreation, etc.)

1.3 Means of delivery individual service providers under Purchase of Client Services Contract with the Bureau of Developmental Disabilities.

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 523 unduplicated count (3mo period)

2.2 Age range All

2.3 Disabilities of person served Same as agency

2.4 Percentage age:

A. 0 - 5 98 individuals (3 mo period)

B. 5 - 18 344 individuals (3 mo period)

C. 18 - on 81 individuals (3 mos period)

D. 30 - 55 Note: we do not collect data by categories other than specified

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped) approximately 66% served are multi-handicapped

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? same as agency

2.6 Persons who need intensive or specialized training/care 523 (3 mo period)

Explain what is meant by those "who need intensive or specialized training/care" needs are not being met through use of generic services or services are not available in home-community setting

2.7 Percentage non-ambulatory data not collected

3.0 Recruitment of Respite Program staff

3.1 Target group citizens of local communities

3.2 Method employment security offices, news media, word of mouth, parent referrals, public relations office of DSHS

3.3 Recruitment materials, tools used/developed Service Provider Interest Application; news releases

4.0 Training of Respite Program staff

4.1 Target group individual service providers and parents

4.2 Method Enrollment in "In-Home Respite Care Training" course; specialty training through a major agency, e.g. U of W, EEU, Childrens Orthopedic Hosp.

4.3 Curriculum Training Manual "In-Home Respite Care Training"

4.4 Training materials; tools used/developed Training Manual

4.5 Source of funding Bureau of Developmental Disabilities, Title XX Vendor Training monies, and Specialized Training component of Home Aid Resources Program

5.0 Community Development

5.1 Media resources Newspapers; T.V.; Radio; agency publications

5.2 Parent education ARC local chapters; Bureau staff communications

5.3 Agency education DSHS Publications - general; Case Services staff training sessions in local offices and field offices with policy manual and WAC's

5.4 Community education Case Services staff; written communications from Administrator; Policy Manual; WAC's; Parent Groups

5.5 Materials; tools used/developed Policy Manual; Published WAC's

6.0 Administration

6.1 Criteria for eligibility of respite services Bureau of Developmental Disabilities eligibility criteria and Goal specified in Individual Program Plan (IPP)

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided 135 Hrs per fiscal year for Respite Care; 6 mos. per fiscal year for Resource Therapies. Exceptions based on individual's documented need and Individual Program Plan (IPP)

6.3 Methods of referral to program Parents, Client Program Coordinator and all others as long as the referral is followed up with parent contact to office and appropriate IPP completed.

6.4 Method of referral to service providers Purchase of Client Services Contract activated with issuance of Delivery Order which describes the specifics of the services to be provided

6.5 Cost of service to client/fees charged by agency/sliding scale No Charge

6.6 Cost of service to agency (operating, indirect, capital costs) All appropriated funds for Home Aid Resources Program go into direct services to the individual client. Other related are within Case Services budget and are not available at this time.

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Voucher direct to service provider

6.8 Provisions for transportation provider mileage paid when traveling in excess of 25 miles round trip and at the established state rate when transporting client

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Bureau of Developmental Disabilities

7.2 State and local regulations, standards, guidelines, zoning RCW; WAC's; Program Policies

7.3 Current, pending, and future legislation No new at this time

8.0 Respite staff/personnel

8.1 Total number staff 900 service providers; 1 Program Administrator; 16 Program Coordinators

8.2a Number supervisory staff/administrator 1 Program Administrator; 16 Program Coordinators

8.2b Professional expertise, special training or skills, relevant experience, etc. Therapists - registered or lisenced; experienced respite providers; para-professionals; technicians; students

8.3a Number direct service staff 900 service providers on contract (not all work at all times)

8.3b Professional expertise, special training or skills, relevant experience, etc. Same as 8.2b

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) estimate 25% of the total 900 or 225

8.4b Professional expertise, special training or skills, relevant experience, etc. Same as 8.2b

8.5 Staffing patterns/system for scheduling direct services staff IPP calls for service, Delivery Order (DO) written, service provider matched and contacted for availability, D.O. Issued for term of service

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, herd money, etc.) 69%

B. State 31%

C. Local None

9.2 Client direct payment None

71

72

9.3 Donations None to program

9.4 Other

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) On Contract with the Bureau of Developmental Disabilities and are part of the IPP planning process

10.2 Agencies (supportive, ancillary, generic) On Contract only when individuals are not available in local community; for specialized equipment; and when otherwise absolutely necessary

10.3 Materials/Tools Purchase of specialized equipment per individual needs and prescription

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.) Same as 10.1

11.2 Agencies (supportive, ancillary, generic) Same as 10.2

11.3 Materials/Tools Same as 10.3

12.0 Strengths/strong points of Respite program Capability of immediate response to individual needs in crisis situations and planned situations; Service providers are from local community; prevention and intervention is a primary goal of the program - prevent institutionalization

13.0 Identified weaknesses/limitations of respite program funds available; attrition of providers to full-time work

73 74

14.0 Evaluation/Accountability On-going data collection:

14.1 Internal fiscal controls; client demographics; Regional operations; service provider performance within Regional Offices and at State office levels

14.2 External Client, parent, or responsible adult verification of services; Service Provider reporting requirements per the Delivery Order.

RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: April 25, 1978 Interviewer: _____

Name of Agency: Cambridge Family and Children's Service, Project H.E.L.O.

Street: 99 Bishop Richard Allen Dr.

City: Cambridge State: Massachusetts Zip: 02139

Program Contact: Dennis Gerber, Kim Snyder

Title: Coordinator, Developmental Therapist Telephone: 617-876-4070

Applied Definition for Respite: Temporary care for families of mentally retarded and/or physically handicapped children, in or out of the home, to meet emergency needs, fulfill vacation plans, obtain routine reprieve, and provide an alternative to institutionalization of the handicapped child.

Part A: Demographics of Agency which is Sponsoring/Governing the Respite Program/Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Primarily urban -- 1 million

1.2 Total population agency serves (e.g., general populace; special segment) General population

1.3 Age range of persons served All

1.4 Disabilities of persons served (primary, secondary and other) All

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped

About 4 %

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? Severe to moderate delays in sensory, motor, language, or cognitive functioning below chronological age

1.6 Percentage of those who require more than average (of popluation served) amount of training/care 4%

What is the amount of staff time needed to provide this? 5-6 hrs. per week (H.E.L.O.) per worker

1.7 Percentage non-ambulatory 2½%

2.0 Types of service offered through agency Counseling, foster care and adoption, family life education, several programs for special needs

3.0 Sources of referral to agency Wide mix of agencies, professionals, individuals

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Board of Directors, Executive Director

4.2 State and local regulations, guidelines, standards, zoning Licensed by Office for Children for foster care and adoption

4.3 Current, pending, and future legislation

5.0 Funding sources (percentage if known)

5.1 Federal

5.2 State Private, non-profit agency with a mix of funding from Mass. Bay United Way, foundations, income

5.3 Local from endowments, etc.

5.4 Other

6.0 Agency's strengths/areas of excellence (Explain/Describe) Individual and group counseling, family life education; expanding programs in area of special needs; vendor for Dept. of Mental Health on Specialized Home Care

7.0 Agency's limitations/areas requiring improvement

art B: Respite Program/Services

1.0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) Through collaboration between CFCS and the state-run community mental health center, Project H.E.L.O. was established in April, 1974, under an 8-year Part F Staffing Grant from H.E.W. The primary goals were to provide preventive services for a high-risk population and to expand community services for preschool children, thereby decreasing the need for institutionalization, through an innovative combination of public and private resources and the creative use of staff.

1.2 Where services are provided

A. In-home Yes

B. Out-of-home Specialized family day care (4 homes)

C. Institutional setting

D. Other

1.3 Means of delivery Paraprofessional child care workers, trained in the agency, work with special needs preschoolers (0-7) in their own homes to provide parent relief, developmental stimulation and other individualized service to the child. The day care homes, also staffed by paraprofessionals, provide 8:30 to 5:30 care for parents who work or are for other reasons unable to provide total care themselves.

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 80 children per year

2.2 Age range 0-8

2.3 Disabilities of person served All developmentally delayed

2.4 Percentage age:

A. 0 - 5 60%

B. 5 - 18 40%

C. 19 - 29

D. 30 - 55

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped) 50%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? Children who have severe to moderate delays in sensory, motor, language, cognitive or social functioning

2.6 Persons who need intensive or specialized training/care 50%

Explain what is meant by those "who need intensive or specialized training/care" Children who cannot perform age appropriate developmental tasks, especially in the area of self-help skills

2.7 Percentage non-ambulatory 20%

3.0 Recruitment of Respite Program staff

3.1 Target group Non-college community persons, including minorities and low-income

3.2 Method Local employment agencies (CETA, etc.), word of mouth, occasional ads and/or flyers

3.3 Recruitment materials, tools used/developed So far not necessary

Training of Respite Program staff

4.1 Target group Paraprofessional child care workers

4.2 Method In-service weekly group, selected speakers/seminars, field placements in special needs classrooms, individual supervision by Coordinator and Developmental Therapist

4.3 Curriculum Administrative, psycho-social and developmental issues around the special needs child; special topics as indicated (alcoholism, nutrition, death & dying, signing, etc.)

4.4 Training materials; tools used/developed Relevant articles and video tapes; use of community resources on child development and retardation

4.5 Source of funding Agency

Community Development

5.1 Media resources Media Resource Center, Fernald State School; Mass. Dept. of Mental Health

5.2 Parent education H.E.L.O. Parent Group, 10 wks/yr.

5.3 Agency education Annual presentation to agency Program Committee and to Board of Directors; joint agency/project committee established to research future funding for the program.

5.4 Community education Occasional newspaper articles; periodic letters to schools, hospitals, mental health and neighborhood clinics, pediatricians, etc.

5.5 Materials; tools used/developed Flyer and back-up information, as needed

6.0 Administration

6.1 Criteria for eligibility of respite services Diagnosis/need; under 7 years of age; Cambridge or Somerville resident

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Minimum 1-day emergency; average 1 year; maximum one family who has been with project since the start (July 1974)

6.3 Methods of referral to program Wide range of public and private resources and professsionals in Greater Boston area

6.4 Method of referral to service providers Assigned by supervisory staff

6.5 Cost of service to client/fees charged by agency/sliding scale Sliding scale, Title XX

6.6 Cost of service to agency (operating, indirect, capital costs) Total cost of program: $194,000

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Direct billing; purchase of service contract with Mass. Dept. of Public Welfare

6.8 Provisions for transportation Offered by Project for parent group only

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Advisory Committee (H.E.L.O.); Board of Directors (C.F.C.S.); Executive Director (agenc

7.2 State and local regulations, standards, guidelines, zoning Day care homes licensed by Office for Children

87 88

7.3 Current, pending, and future legislation N.A.

8.0 Respite staff/personnel

8.1 Total number staff 17½

8.2a Number supervisory staff/administrator 2 (Coordinator and Director)

8.2b Professional expertise, special training or skills, relevant experience, etc. Both MSW; Director has administrative background, Coordinator experience with training, supervision, special needs population

8.3a Number direct service staff 13 paraprofessional child care workers

8.3b Professional expertise, special training or skills, relevant experience, etc. High school diploma, some experience with children

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) 2 (OT, pt-time social worker)

8.4b Professional expertise, special training or skills, relevant experience, etc. OTR, MSW

8.5 Staffing patterns/system for scheduling direct services staff 1-1; child care workers each assigned 3-5 children

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) H.E.W. Part F Staffing Grant $110,829/yr.

B. State Dept. of Public Welfare, Family Life Education Contract $15,600 (1977)

C. Local Dept. of Education, reimbursement under Chapter 766 $ 3,840 "

9.2 Client direct payment About $4,000/yr.

9.3 Donations $ 2,000

9.4 Other Advisory Committee Benefit: $1,250

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) There are many paraprofessionals willing to receive training, given the money and programs

10.2 Agencies (supportive, ancillary, generic) Preschool Unit, Cambridge-Somerville Mental Health & Retardation Ctr.; Cambridge-Somerville Office for Children; Neighborhood Support Systems for Infants (Somerville/Medford)

10.3 Materials/Tools

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.) In process of being assessed at local and state level

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Respite program Provide the only special needs day care in the cities of Cambridge and Somerville

13.0 Identified weaknesses/limitations of respite program No overnight respite provided

13 Evaluation/Accountability

14.1 Internal H.E.L.O. Advisory Committee

14.2 External H.E.W. site visit; in-depth consumer survey, 1977

RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT
CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS
AGENCY SURVEY
FEBRUARY, 1978

Date: April 20, 1978 Interviewer: _____

Name of Agency: Systems Unlimited, Inc., Family and Child Training (FACT) program

Street 1020 William

City: Iowa City, State: Iowa Zip: 52240

Program Contact: Benny Leonard, Executive Director or Gratia Koch, Coordinator, FACT program

Title: _____ Telephone: 319 338 9212

Applied Definition for Respite: _____

Note: The following information pertains to the FACT program, which is a component of Systems Unlimited, Inc.

Part A: Demographics of Agency which is Sponsoring/Gorerning the Respite Program/Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Johnson, Washington, Iowa & Surrounding (Iowa) Counties

1.2 Total population agency serves (e.g., general populace; special segment) Title XX (Income Guidelines)

1.3 Age range of persons served 0-18 (Expanding to serve adults)

1.4 Disabilities of persons served (primary, secondary and other) "Developmental Disabilities"

Primary - Mental Retardation, Severe/profound

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped 75%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? AAMD & other definitions are used by D.S.S., Hospital School (U. of Iowa) etc. A I & E program is beginning in our area.

1.6 Percentage of those who require more than average (of population served) amount of traning/care 60%

What is the amount of staff time needed to provide this? 5-10 hours/week of contact

1.7 Percentage non-ambulatory 50%

2.0 Types of service offered through agency Counseling, Respite Care, Parent Training, Recreation Therapy

3.0 Sources of referral to agency Department of Social Services & District Administrater of The Department of Social Services.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees County Board of Social Welfare, Systems Unlimited Board of Directors

4.2 State and local regulations, guidelines, standards, zoning Department of Social Services, Developmental Disabilities Guidelines and Iowa Code, (Title XX Guidelines)

4.3 Current, pending, and future legislation

5.0 Funding sources (percentage if known)

5.1 Federal

5.2 State 100% (Foster Care monies, under Title XX guidelines)

96 5.3 Local (pending) local money (county) for adult services

5.4 Other

6.0 Agency's strengths/areas of excellence (explain/Describe) Flexibility, comprehensive nature of service, intensive (5 to 10 hours per week) intervention. We can provide service during those hours (evenings and weekends)

~~When we're needed. Serving the total family, with parents as coordinators of service.~~

7.0 Agency's limitiations/areas requiring improvement We currently serve only those families eligible for Title XX services. We need funding to serve middle income families.

Part B: Respite Program/Services

8.0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) The FACT program began taking referrals in June of 1977. Prior to this, parents of disabled children had requested such services from Systems Unlimited, Inc., which is a private non-profit agency which provides residential and other services to developmentally disabled children and adults. Benny Leonard (Executive Director) and Donna Hinkle (Asst. Director) began the program, with the cooperation of the Johnson County Department of Social Services.

1.2 Where services are provided

A. In-home Home visits are made several times/week.

B. Out-of-home Utilizing community resources, including Systems Unlimited.

C. Institutional setting

D. Other

1.3 Means of delivery Primary: home visits by child-care workers or by the educational consultant, social worker, or coordinator.

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 12

2.2 Age range 6 months - 13 years

2.3 Disabilities of person served Severe/profound MR(9) Trainable MR (3)

2.4 Percentage age:

A. 0 - 5 6

B. 5 - 18 6

C. 19- 29

D. 30 - 55

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped) 75%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? AAMD & other definitions used by D.S.S., U of I Hospital School (primary diagnosis)

2.6 Persons who need intensive or specialized training/care Non ambulatory with complicating factors, ie siezures, feeding difficulties, etc, or more than one disabled child in the family.

Explain what is meant by those "who need intensive or specialized training/care"

2.7 Percentage non-ambulatory 33%

100 101

3.0 Recruitment of Respite Program staff

3.1 Target group Persons knowledgeable of in-home service and developmental disabilities

3.2 Method Equal opportunities practices

3.3 Recruitment materials, tools used/developed _____

.0 Training of Respite Program staff

4.1 Target group _____

4.2 Method Child-specific training utilizing the staff of University of Iowa Hospital School (esp. the outpatient team) Grant Wood Area Education Agency and other agencies involved with the child and family.

4.3 Curriculum _____

4.4 Training materials; tools used/developed films on dental hygiene the operation of Systems Unlimited and training involving daily activities

4.5 Source of funding Department of social services

.0 Community Development

5.1 Media resources Systems Unlimited, Inc. film and brochures prepared with help of local specialists.

5.2 Parent education three parent group meetings, and assistance with Grant Wood AEA parent meetings.

5.3 Agency education Introductory visits to explain FACT program to University Hospital Outpatient team, visiting nurses, other agencies

5.4 Community education _____

5.5 Materials; tools used/developed (Systems Inc.) Picture album, photo display board, brochures, slide presentation, film

6.0 Administration

6.1 Criteria for eligibility of respite services Title XX (family must meet low-income guidelines), developmental disability

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Each family receives approximately 5 hours/week of direct-contact intervention, roughly 1/3 of this time could be classified "respite"

6.3 Methods of referral to program Department of Social Services refers to FACT

6.4 Method of referral to service providers FACT staff contacts appropriate agencies

6.5 Cost of service to client/fees charged by agency/sliding scale none, no cost

6.6 Cost of service to agency (operating, indirect, capital costs) ~~$12.60~~ 19.60 per contact hour.

6.7 System of payment (broker, voucher, direct, to service provider, etc.) State DSS - Foster care

6.8 Provisions for transportation FACT staff provides transportation

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Systems Unlimited Board of Directors

7.2 State and local regulations, standards, guidelines, zoning Guidelines of the Iowa Department of Social Services.

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7.3 Current, pending, and future legislation _____

8.0 Respite staff/personnel

8.1 Total number staff 5

8.2a Number supervisory staff/administrator 1 (Coordinator)

8.2b Professional expertise, special training or skills, relevant experience, etc. MSW, 4 years Experience with Developmental Disabilities

8.3a Number direct service staff 4

8.3b Professional expertise, special training or skills, relevant experience, etc. BASW, BA (Special Education)

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) We have to University of Iowa, Grant Wood AEA and to Hospital School

8.4b Professional expertise, special training or skills, relevant experience, etc. _____

8.5 Staffing patterns/system for scheduling direct services staff two staff are trained in Special Education

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) _____

B. State State foster care money

C. Local Funding through County Board of Supervisors (Mental Health Institutional Funds)

9.2 Client direct payment None

9.3 Donations

9.4 Other

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) Systems Unlimited, Inc., staff and facilities

10.2 Agencies (supportive, ancillary, gereric) The Johnson County ARC provides respite care at no cost to Johnson County residents.

10.3 Materials/Tools

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.) We are unable to serve those families who do not meet Title XX guidelines

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Respite program Flexibility, inclusion of recreation therapy, focus on family as a whole rather than the disabled individual, many resources in the area.

13.0 Identified weaknesses/limitations of respite program Funding not available to serve middle-income families.

Evaluation/Accountability

14.1 Internal ~~Coordinator evaluates staff yearly~~

14.2 External The Department of Social Services is responsible for evaluation of program effectiveness.

FAMILY RESOURCE SERVICES

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

JANUARY, 1980

Date: January 21, 1980 Interviewer: Cary Carron

Name of Agency: Archdiocese of Denver Ministry to the Handicapped

Street: 2141 South Zenobia Street

City: Denver State: Colorado Zip: 80219

Program Contact: Gary Haug

Title: Respite Care Coordinator Telephone: (303)936-7288

Applied Definition for Family Resource Services Respite service is appropriate, short term temporary care, provided in a variety of settings, for the care of developmentally disabled for a period of time on a regular or intermittent basis to: 1) meet planned or emergency needs of the family and 2) restore and/or maintain harmony within the family unit.

Part A: Demographics of Agency which is Sponsoring/Governing the Family Resource Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) 4 counties making up the Denver metropolitan area

1.2 Total population agency serves (e.g., general populace; special segment) developmentally disabled people

1.3 Age range of persons served no age limit

1.4 Disabilities of persons served (primary, secondary and other) children and adults who are mentally and physically disabled.

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped ____

15%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority?

1.6 Percentage of those who require more than average (of population served) amount of training/care

17%

1.7 Percentage none-ambulatory 26%

2.0 Types of service offered through agency Respite Care in and out of home follow-up counseling, family and community education

3.0 Sources of referral to agency public and private agencies, private physicians, psychologists, schools, associations for retarded citizens (ARC's)

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Cary Carron, 5 ARC Executive Directors

4.2 State and local regulations, guidelines, standards, zoning Division for Developmental Disabilities and Colorado Department of Social Services

4.3 Current, pending, and future legislation Funding

5.0 Funding sources (percentage if known)

5.1 Federal

5.2 State X

5.3 Local

5.4 Other X Archdiocese of Denver (Private) ARC's

6.0 Agency's strengths/areas of excellence (Explain/Describe) The simplicity of administration allows for creative and flexible responses to individualized needs of clients and families. The credibility of the Director and agency enhances continuity and quality of services. Good working relationship with community Resource people.

7.0 Agency's limitations/ areas requiring improvement Lack of funds to expand services.

Part B. Family Resource Services/Program

1.0 Program Abstract (Please include any formal literature about the Family Resource Services program.)

Description and Components of Family Resource Services Program

1.1 Historical Perspective (how, and when program was started) Need for respite care was identified by the Denver Association for Retarded Citizens. At their request, Cary Carron, Director of the Ministry to the Handicapped, Archdiocese of Denver, started the respite care program in January, 1976, using trained private homes in the community to provide respite care.

1.2 Where services are provided

A. In-home X

B. Out-of-home X

C. Institutional setting

D. Other

1.3 Means of delivery Individualized

2.0 Population served through Family Resource Services (note: percentages may overlap)

2.1 Total number served FY1978-79 served 310

2.2 Age range No limit

2.3 Disabilities of person served All developmental disabilities

2.4 Percentage age:

A. 0 - 5 33%

B. 5 - 18 49.5%

C. 19 - 29 9%

D. 30 - 55 6.5%

E. 55 and over 2%

2.5 Percentage of severe/profound (multi-handicapped) 15%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? We use AAMD definitions

2.6 Persons who need intensive or specialized training/care 65%

Explain what is meant by those "who need intensive or specialized training/care" Medically fragile persons or those with developmental and/or behavioral problems.

2.7 Percentage non-ambulatory 26%

3.0 Recruitment of Family Resource Services Program staff

118

3.1 Target group Interested caring people in the community. (We do the training.)

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3.2 Method Church Bulletins, media resources, word of mouth, recommendation

3.3 Recruitment materials, tools used/developed Word of mouth, church bulletin, personal contact

4.0 Training of Family Resource Services

4.1 Target group Respite care providers

4.2 Method Training sessions and in-service provided by families.

4.3 Curriculum Basic understanding developmental disabilities, Medical/nursing aspects, legal aspects, parents' panels.

4.4 Training materials; tools used/ developed Training manual, visual aids. actual clients.

4.5 Source of funding Respite Care Budget

5.0 Community Development

5.1 Media resources ARC Newsletters, Church Bulletins, P.S.A. radio and television

5.2 Parent education Each training session and as needed

5.3 Agency education Continuing education, seminars, workshops, and active participation on private and public agency committees.

5.4 Community education Presentation of workshops, lectures and films.

5.5 Materials; tools used/ developed see 5.1

6.0 Administration

6.1 Criteria for eligibility of Family Resource Services Clients live in the Denver Metropolitan Area and diagnosed as developmentally disabled.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Duration is from an hour to 30 consecutive days unless there are extenuating circumstances.

6.3 Methods of referral to program Telephone or direct contact with Respite Care staff.

6.4 Method of referral to service providers Same

6.5 Cost of service to client/fees charged by agency/sliding scale $1 an hour or $10/day. More involved cases negotiable. - sliding scale.

6.6 Cost of service to agency (operating, indirect, capital costs) N/A - Program cost $36,000 FY 1978-79

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Consumer pays provider directly - supplemental assistance by Archdiocese/voucher.

6.8 Provisions for transportation None (consumer responsibility)

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Two - Respite Care Director and Coordinator

7.2 State and local regulations, standards, guidelines, zoning Agency had become a Child Placement Agency and homes providing 72 hours Respite Care in any one week must be certified - Colorado State Department of Social Services.

7.3 Current, pending, and future legislation Colorado Legislatures Joint-Budget Committee for Continuation of State funding.

8.0 Family Resource Services staff/personnel

8.1 Total number staff 2

8.2a Number supervisory staff/administrator 1

8.2b Professional expertise, special training or skills, relevant experience, etc. Director has a Masters degree in nursing, Post-graduate education Special Education and 20 years of experience in field.

8.3a Number direct service staff 102

8.3b Professional expertise, special training or skills, relevant experience, etc. see 4.3 and experience.

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) Unlimited

8.4b Professional expertise, special training or skills, relevant experience, etc. Professionals in all areas.

8.5 Staffing patterns/system for scheduling direct services staff N/A

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc)

B. State X

C. Local X

9.2 Client direct payment Yes

9.3 Donations None

9.4 Other ARC's

10.0 Available Family Resource Services Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) J.F.K. Child Development Center

10.2 Agencies (supportive, ancillary, generic) Public Schools, ARC's, Community Center Boards

10.3 Materials/Tools IHP and IPP - pre and post respite care

11.0 Needed Family Resource Services

11.1 Persons (parents, professionals, etc.) Providers

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Family Resource Services program Excellent care givers - community based; keeps family unit intact, good personal relationship with comsumers and providers.

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13.0 Identified weaknesses/limitations of Family Resource Services Expansion - especially funding and staff

14.0 Evaluation/Accountability

14.1 Internal Client records - follow up

14.2 External Consumer/provider evaluation of services

15.0 General Comments

16.0 Names and addresses of other programs and agencies providing this service that you are aware of and would recommend, etc.,

RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: _____ Interviewer: _____

Name of Agency: Kansas Children's Service League

Street: 2053 Kansas Avenue, Box 5314

City: Topeka State: Kansas Zip: 66605

Program Contact: Marge Mintun

Title: Administrative Supervisor Telephone: 1-913-232-0543

Applied Definition for Respite: A service designed to provide temporary placement, up to 30 days, to developmentally disabled children of families who need relief from the day-to-day management of the disabled child.

Part A: Demographics of Agency which is Sponsoring/Governing the Respite Program/Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Statewide Agency--Rural-urban and suburban families.

1.2 Total population agency serves (e.g., general populace; special segment) General population of children and their

1.3 Age range of persons served Children 0-18 years and their families

1.4 Disabilities of persons served (primary, secondary and other) Agency does not designate a disability except for the Respite Care Program

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped

One percent (1%)

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? Disability of a person who is attributable to a mental and/or physical impairment which results in substantial functional limitation.

1.6 Percentage of those who require more than average (of popluation served) amount of training/care Respite Care-1%

What is the amount of staff time needed to provide this? One social worker; 1/5 Supervisor; 1/5 clerical.

1.7 Percentage non-ambulatory .5%

2.0 Types of service offered through agency Pregnancy Counseling; adoption; Parent Ed.; Respite Care; Home Start; Emergency short -term Foster Care; Respite family care; Parent-child/Family Counseling.

3.0 Sources of referral to agency Public and private agencies, Courts, schools, other community sources and self referral.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Statewide Board of Directors

4.2 State and local regulations, guidelines, standards, zoning Licensing by State Department of Social, Rehabilitation Services - Health Department

4.3 Current, pending, and future legislation N/A

5.0 Funding sources (percentage if known)

5.1 Federal Home Start; Emergency Foster Care contracts and Black Adoption Program contract.

5.2 State Emergency Foster Care contracts.

5.3 Local United Way (for traditional programs) and Topeka Association for Retarded Citizens (Respite)

132 5.4 Other Fees, bequests, income from investments. 133

6.0 Agency's strengths/areas of excellence (Explain/Describe) Long history of high standards of service for children, member of Child Welfare League of America, innovative and responsive to community needs.

7.0 Agency's limitations/areas requiring improvement Agency is moving to establish a solid diversified funding base.

art B: Respite Program/Services

1.0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started)

The program was started as a pilot project in 1977 in response to a request from Topeka Association of Retarded Citizens. Kansas Children's Service League appropriated money to fund 100 childcare days. Following completion of this project, a proposal was submitted to Topeka Association for Retarded Citizens in December, 1977 which resulted in a small start-up grant. Continued funding on a Purchase of Service basis has been submitted.

1.2 Where services are provided

A. In-home

B. Out-of-home (Respite) Family foster care.

C. Institutional setting

D. Other

1.3 Means of delivery One to Thirty days of care in twelve month period.

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 30 children

2.2 Age range 1-15 years

2.3 Disabilities of person served Mentally retarded with physical handicaps.

2.4 Percentage age:

A. 0 - 5 70%

B. 5 - 18 30%

C. 19 - 29

D. 30 - 55

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped) 60%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority?

2.6 Persons who need intensive or specialized training/care N/A

Explain what is meant by those "who need intensive or specialized training/care"

2.7 Percentage non-ambulatory 70%

3.0 Recruitment of Respite Program staff

3.1 Target group Respite Foster Parents

3.2 Method Outreach (talks; letters) in the community; newspaper ads, etc.

3.3 Recruitment materials, tools used/developed _____

4.0 Training of Respite Program staff

4.1 Target group Foster parents

4.2 Method Structured classes and observation of class at Day Care Center for mentally disabled.

4.3 Curriculum _____

4.4 Training materials; tools used/developed _____

4.5 Source of funding Topeka Association of Retarded Citizens grant.

5.0 Community Development

5.1 Media resources Program has not reached this stage yet.

5.2 Parent education _____

5.3 Agency education _____

5.4 Community education _____

5.5 Materials; tools used/developed _____

6.0 Administration

6.1 Criteria for eligibility of respite services Must be family with a child under 18 years who is diagnosed as mentally and/or physically disabled.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Up to 30 days in 12 month sequence.

6.3 Methods of referral to program Topeka Association of Retarded Citizens or any community organization or person.

6.4 Method of referral to service providers Kansas Children's Service League is service provider - foster parents are under Agency jurisdiction.

6.5 Cost of service to client/fees charged by agency/sliding scale Sliding fee scale according to income.

6.6 Cost of service to agency (operating, indirect, capital costs) $33 per diem.

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Agency receives direct payment from parent and pays foster parents.

6.8 Provisions for transportation Kansas Children's Service League reimburses foster parents for transportation.

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Agency Board of Directors (see 4.0)

7.2 State and local regulations, standards, guidelines, zoning

7.3 Current, pending, and future legislation _____

_____

8.0 Respite staff/personnel

8.1 Total number staff One and three-fifths (1 3/5) staff; one full time (caseworker) coordinator.

8.2a Number supervisory staff/administrator Casework supervisor and administrative supervisor.

8.2b Professional expertise, special training or skills, relevant experience, etc. Child welfare specialists; Registered nurse; foster care and family counseling experience.

8.3a Number direct service staff N/A

8.3b Professional expertise, special training or skills, relevant experience, etc. _____

N/A

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) N/A

8.4b Professional expertise, special training or skills, relevant experience, etc. _____

_____

8.5 Staffing patterns/system for scheduling direct services staff N/A

_____

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) None

B. State None

C. Local Topeka Association of Retarded Citizens

9.2 Client direct payment Sliding scale

9.3 Donations None

9.4 Other Kansas Children's Service League

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) Parent and staff - Topeka Association of Retarded Citizens

10.2 Agencies (supportive, ancillary, generic) Topeka Association of Retarded Citizens - Kansas Neurological Institute.

10.3 Materials/Tools N/A

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.)

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Respite program Part of generic agency offering wide variety of child welfare services to these families.

13.0 Identified weaknesses/limitations of respite program Less than a year old - growing pains of new programs.

14.0 Evaluation/Accountability

14.1 Internal Consumer and providers evaluate every placement.

14.2 External Overall agency evaluation; State licensing accountability to Topeka Association of Retarded Citizens for additional funding.

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RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SITE SURVEY QUESTIONNAIRE

Date: April 1977 Interviewer: Dianne Smith

Name of Agency: San Diego Association for the Retarded

Street: 33035 "G" St.,

City: San Diego, State: California Zip: 92102

Program Contact: Mary Jim Martin

Title: Respite Coordinator Telephone: 714-234-2264

Applied Definition for Respite: Service which provides in-home relief to parents or caretakers of handicapped persons on a temporary basis in order to make it possible for family stability to be maintained.

PROGRAM DESCRIPTION

Environment

In-home only Out of home

Established residential facility Other:

Components

Services Overnight - 2 to 12 hours - 3 to 10 days - contracted group sitter services; training; intensive training of staff;

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Training

Staff _____ Clients _____

Parents _____ Volunteers _____

Students _____ Community PR/PE

Other _____

Tools used/developed "Images of epilepsy" on slide show, video tape, work of PT's, OT's and speech therapists.

Clients

Number served 350 Age Range Birth to death Percentage Adults _____

Disabilities All DD - 90% of which are MR

Percentage Severe/Profound (Multiple) 30%

Criteria for admission The handicapped person.

Time of service limits Limit 3 to 10 days - 2 to 12 hours - overnite requires advance notice

Referral source anywhere

Fees/charges Family pays the worker directly - $1.00 or $1.50 an hour the suggested rate although that's negotiated between the family & the worker.

Management

Total staff 55 Direct Service Staff 53

Staffing patterns 1 to 1 - 1 to 4 in a professional surrounding at $1.00 an hour per child.

Governing/decision body Association or Advisory Committee

Funding Direct payment with some ' vendorization in a local regional center.

Resources

People Deanna Shoob

Agencies Syracuse Hospital for Autistic - American Red Cross

Materials

Identified Needs Funding -Spanish speaking families to provide respite rural area part time employee to coordinate respite services and recruit respite providers.

Competencies Training program which is general for DD

AGENCY DEMOGRAPHICS

Population

Service Area San Diego County

Agency 500

Age range ~~Birth to death~~

Disabilities 15% are severe and profound

Percentage severe/profound/multiple disabilities

Service

Types of agency Private, not for profit

Services offered Wide Range from infants to workshop including educational & transportation.

Source of referral Anywhere

Agency competencies Workshop and activity training center.

Management

Governing/decision body Board

Funding 60% United Way - vendor and private donations.

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FAMILY RESOURCE SERVICES

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

JANUARY, 1980

Date: April 23, 1978 Interviewer: _____

Name of Agency: Child Care Assistance Program for Special Children, Inc. (CAPS)

Street: Box 1217

City: Springfield State: Virginia Zip: 22151

Program Contact: Mrs. Deanna Shoob

Title: President Telephone: (703) 256-2321

Applied Definition for Family Resource Services Short term or temporary relief care in or out of the home for vacations, emergencies, routine reprieve or as an alternative to institutionalization of the handicapped individual.

Part A: Demographics of Agency which is Sponsoring/Governing the Family Resource Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Northern Virginia

1.2 Total population agency serves (e.g., general populace; special segment) Approximately 1 million

1.3 Age range of persons served birth to elderly

1.4 Disabilities of persons served (primary, secondary and other) all disabilities

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped ____

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority?

1.6 Percentage of those who require more than average (of population served) amount of training/care

1.7 Percentage none-ambulatory

2.0 Types of service offered through agency Respite care

3.0 Sources of referral to agency social workers, schools, hospitals, parents, etc.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees volunteer board of directors

4.2 State and local regulations, guidelines, standards, zoning

4.3 Current, pending, and future legislation

5.0 Funding sources (percentage if known)

5.1 Federal

5.2 State 50%

5.3 Local 20%

5.4 Other (Private contributions) 30%

6.0 Agency's strengths/areas of excellence (Explain/Describe) community-based parent involvement, lack of "red tape" cost effective, H16H usage rate.

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7.0 Agency's limitations/ areas requiring improvement

Part B. Family Resource Services/Program

1.0 Program Abstract (Please include any formal literature about the Family Resource Services program.)

Description and Components of Family Resource Services Program

1.1 Historical Perspective (how, and when program was started) Started in 1969 by parent of mentally retarded child - initiated by woman's club in No. Virginia as community improvement project. Incorporated in late 1970. Program disbanded in 1973. Re-organized in 1976 by parent of mentally retarded child.

1.2 Where services are provided

A. In-home X

B. Out-of-home X

C. Institutional setting

D. Other

1.3 Means of delivery Parent or provider or service.

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2.0 Population served through Family Resource Services (note: percentages may overlap)

2.1 Total number served 250

2.2 Age range birth to elderly

2.3 Disabilities of person served all disabilities

2.4 Percentage age:

A. 0 - 5 all age groups

B. 5 - 18

C. 19 - 29

D. 30 - 55

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped)

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority?

2.6 Persons who need intensive or specialized training/care

Explain what is meant by those "who need intensive or specialized training/care"

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2.7 Percentage non-ambulatory

3.0 Recruitment of Family Resource Services Program staff

3.1 Target group educators, P.T., O.T., nurses, housewives, etc.

3.2 Method Use of media of all types, flyers, word of mouth

3.3 Recruitment materials, tools used/developed _____

4.0 Training of Family Resource Services

4.1 Target group same as in 3.1

4.2 Method 2-part training session once every 3 months

4.3 Curriculum D. D. overview, first aid, seizure control, P.T., behavior management, panel discussion.

4.4 Training materials; tools used/ developed Handouts

4.5 Source of funding not necessary

5.0 Community Development

5.1 Media resources all

5.2 Parent education appear before PTA

5.3 Agency education ongoing

5.4 Community education ongoing

5.5 Materials; tools used/ developed _____

6.0 Administration

6.1 Criteria for eligibility of Family Resource Services mentally retarded and/or physically handicapped

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided hourly, daily, weekend, weekly

6.3 Methods of referral to program all

6.4 Method of referral to service providers by director/registrar of CAPS

6.5 Cost of service to client/fees charged by agency/sliding scale $1.50 per hr. 1st two hours, $1.00 each $1.00 each additional hour. $15.00 overnight care

6.6 Cost of service to agency (operating, indirect, capital costs) Total FY 1978 operating budget: $12,700

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Family pays directly to provider of service for respite care unless subsidized (part or full) by CAPS

6.8 Provisions for transportation arranged between parent and provider

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees

7.2 State and local regulations, standards, guidelines, zoning

7.3 Current, pending, and future legislation _____

_____

8.0 Family Resource Services staff/personnel

8.1 Total number staff 1 part-time (25 hours./wk) Director/Registrar

8.2a Number supervisory staff/administrator 10 board of directors

8.2b Professional expertise, special training or skills, relevant experience, etc. Professional consultants and clinicians for training and consultation

8.3a Number direct service staff approximately 50

8.3b Professional expertise, special training or skills, relevant experience, etc. varied

_____

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) clinicians for training - 3

8.4b Professional expertise, special training or skills, relevant experience, etc. _____

_____

8.5 Staffing patterns/system for scheduling direct services staff _____

_____

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc) _____

B. State _____

C. Local _____

9.2 Client direct payment _____

9.3 Donations yes

9.4 Other fees for registration - one-time $10.00 charge

10.0 Available Family Resource Services Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.)

10.2 Agencies (supportive, ancillary, generic)

10.3 Materials/Tools

11.0 Needed Family Resource Services

11.1 Persons (parents, professionals, etc.)

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Family Resource Services program

13.0 Identified weaknesses/limitations of Family Resource Services

14.0 Evaluation/Accountability

14.1 Internal Follow-up evaluations to parent and provider of service. newsletter to parents and provider.

14.2 External Documentation of program objectives to state and local government funding services

15.0 General Comments

16.0 Names and addresses of other programs and agencies providing this service that you are aware of and would recommend, etc.,

RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: April 24, 1978 Interviewer: Kathleen Ross

Name of Agency: Coastal Home Respite Care Project

Street: 1609 Newcastle Street, Room 309

City: Brunswick State: Georgia Zip: 31520

Program Contact: Chuck Ballance

Title: Project Director Telephone: (912) 264-7300

Applied Definition for Respite: Providing families with a member who is developmentally disabled a Home Companion (provider) who provides relief when needed and allows the family an opportunity for leisure activities.

Part A: Demographics of Agency which is Sponsoring/Governing the Respite Program/Services

1.0 Population served by entire agency Glynn County Board of Health

1.1 Geographic area (e.g., state, counties, # people, rural or urban) 1970 census 50,528, DD 2,946- Glynn Co.

1.2 Total population agency serves (e.g., general populace; special segment) entire population

1.3 Age range of persons served all ages

1.4 Disabilities of persons served (primary, secondary and other) any disabilities which come under the governing rules and regulations of the Board of Health

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1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped ____

unknown

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? I.Q. below 35 with two or more physical disabilities

1.6 Percentage of those who require more than average (of popluation served) amount of training/care ____

What is the amount of staff time needed to provide this?

1.7 Percentage non-ambulatory

2.0 Types of service offered through agency Memtal Health, Physical Health, V.R., MR., Drug and Alcohol Counseling, crisis line

3.0 Sources of referral to agency sister agencies, personal contact, advertisements

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Coastal Area Mental Health Center assumes administrative responsibility, Center's Developmental Service Chief assuming supervision responsibility for Respite Director.

4.2 State and local regulations, guidelines, standards, zoning

Contract with Glynn County Mental Health Association for hiring of project director and related costs

4.3 Current, pending, and future legislation

5.0 Funding sources (percentage if known)

5.1 Federal Not Known

5.2 State Not Known

5.3 Local Not Known

5.4 Other

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6.0 Agency's strengths/areas of excellence (Explain/Describe)

7.0 Agency's limitations/areas requiring improvement

art B: Respite Program/Services

1.0 Program Abstract (Please include any formal literature about the respite program.)

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) The program offically started on April 1,1977 when project director assumed his position, Idea for program was started at Georgia Association for Retarded Citizens state conference in 1976. A narrative is provided in the grant proposal.

1.2 Where services are provided

A. In-home Home Companion stays with person who has a developmental disability in the their home.

B. Out-of-home Bed space has been made avialable at the local Group Home .

C. Institutional setting

D. Other Person with developmental disability can stay, if need be, at Home Companion's home.

1.3 Means of delivery Dependent upon needs and geographic location of client. Home Companion assigned to family based on capibilities and geographic location.

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2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served 94 registered, 36 having been served a total of 248 times

2.2 Age range all ages

2.3 Disabilities of person served Mentally Retarded, cerebral palsy, epilepsy, autism

2.4 Percentage age:

A. 0 - 5 17%

B. 5 - 18 41%

C. 19 - 29 17%

D. 30 - 55 20%

E. 55 and over 5%

2.5 Percentage of severe/profound (multi-handicapped) unable to determine

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? I.Q. below 35 with two or more disiblilites

2.6 Persons who need intensive or specialized training/care 12

Explain what is meant by those "who need intensive or specialized training/care" handicapps involve special training in order to take care of individuals-- usually provided by parent/guardian

2.7 Percentage non-ambulatory 10%

3.0 Recruitment of Respite Program staff

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3.1 Target group anyone 18 or over, special consideration is given to anyone 55 or over

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3.2 Method advertisements and word of mouth, placements thru employment agency

3.3 Recruitment materials, tools used/developed ___ regristration for both clients adn Home Companions (forms)

4.0 Training of Respite Program staff

4.1 Target group all registered Home Companions

4.2 Method Short mini courses in areas of normalization, psychology in the different levels of mental retardation emergency lst aid, recreational therapy, medication-siezure control

4.3 Curriculum completion of mini courses and 10 hours work in Glynn or Liberty Co. Training Centers

4.4 Training materials; tools used/developed local area professionals, Respite Advisory Council and Ga. D.D. council will be developing training manuel

4.5 Source of funding Developmental Disabilities Assistance and Bill of Rights Act--Federal

5.0 Community Development

5.1 Media resources newspaper articles and radio public service announcements

5.2 Parent education Individual counseling as necessary

5.3 Agency education various in-service when appropiate

5.4 Community education Director given several presentations to local service groups, also a brochure explaining program has been circulated.

5.5 Materials; tools used/developed brochure, and presentation for service groups

6.0 Administration

6.1 Criteria for eligibility of respite services Meet defination of developmentally disabled

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Depends on request-no limitations

6.3 Methods of referral to program referral thru other agencies, word of mouth, newspaper and radio

6.4 Method of referral to service providers family calls supervisory staff makes request then staff calls Home Companion which was predetermined by assignments.

6.5 Cost of service to client/fees charged by agency/sliding scale none at this time

6.6 Cost of service to agency (operating, indirect, capital costs) $1.60 Stipend per hr. for Home Companion

6.7 System of payment (broker, voucher, direct, to service provider, etc.) paycheck issued every two weeks based on time sheet turned in by Home Companion

6.8 Provisions for transportation family provides transportation if possible- when H.C. drives personal automobile reimbursed $.12 per mile.

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Project Director, Areas Retardation Service Chief, Advisory Council

184 7.2 State and local regulations, standards, guidelines, zoning 185

Policy Advisory Group to develop standards and policies for Project

7.3 Current, pending, and future legislation Recommendations to do something state-wide

8.0 Respite staff/personnel

8.1 Total number staff 21

8.2a Number supervisory staff/administrator 3

8.2b Professional expertise, special training or skills, relevant experience, etc. Project Director-B.A. Psy., and 5 years experience; Social Worker (50%)- 24 years as county extension agent; Vista-no previous experience

8.3a Number direct service staff 18

8.3b Professional expertise, special training or skills, relevant experience, etc. 2 home companions have experience in mental hospital situations

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) none on projects payroll

8.4b Professional expertise, special training or skills, relevant experience, etc. 2 training programs for home companion taken place; 2 training programs planned

8.5 Staffing patterns/system for scheduling direct services staff Assignments made by supervisory staff

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) Grant- Developmentally Disabled Assistance Act

B. State none

C. Local 35% matching funds

9.2 Client direct payment none

9.3 Donations some

9.4 Other

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) some parents are on staff as home companions

10.2 Agencies (supportive, ancillary, generic) Community Training Centers for DD (referrals, training, ~~diagnostic~~ services); Commitment from Coastal Area Planning and Development has not followed through

10.3 Materials/Tools

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.)

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Respite program ~~Resources available such as training center for mentally retarded~~ used as a referral source and training center for staff; also group home beds make respite available under any circumstanc also increased public awareness.

13.0 Identified weaknesses/limitations of respite program ~~being a demonstation project had nothing to go by or resources~~ available. ~~Recruitment of Senior Citizens presents dome difficulties;~~

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.0 Evaluation/Accountability

14.1 Internal developing a evaluation form, also have written 1st year's evaluation and 2nd year's 6month reports

14.2 External Joint evaluation by Ca. Council on DD and State Administrative Agency

FAMILY RESOURCE SERVICES

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

JANUARY, 1980

Date: 4-21-78 Interviewer: _____

Name of Agency: Esperanza Para Nuestros Ninos

Street: 1820 Valdera, S.W. P.O. Box 12212

City: Albuquerque State: New Mexico Zip: 87195

Program Contact: Kathleen Hickman

Title: Residential Coordinator Telephone: (505)-873-0600

Applied Definition for Family Resource Services Short term care, in an agency facility, for emergency relief care, not to exceed 90 consecutive days. This may be offered during daytime hours and/or overnight.

Part A: Demographics of Agency which is Sponsoring/Governing the Family Resource Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) 3 counties; urban and rural

1.2 Total population agency serves (e.g., general populace; special segment) Developmentally disabled persons

1.3 Age range of persons served birth - 18 yrs.

1.4 Disabilities of persons served (primary, secondary and other) all developmental disabilities

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped ____

57%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? Esperanza uses the definition put forth by James Tauney, Ph.D.

1.6 Percentage of those who require more than average (of population served) amount of training/care 100%

1.7 Percentage none-ambulatory 31%

2.0 Types of service offered through agency Infant stimulation; pre-school; adolescent group home; respite care.

3.0 Sources of referral to agency Physicians, schools, health and social service agencies, parents.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Board of Directors - 87% parents

4.2 State and local regulations, guidelines, standards, zoning Health and Social Services Department does all licensing; fire inspections every 6 months; contact compliances and program audits.

4.3 Current, pending, and future legislation none

5.0 Funding sources (percentage if known)

5.1 Federal 67%

5.2 State 22%

5.3 Local 11%

5.4 Other

6.0 Agency's strengths/areas of excellence (Explain/Describe) Use of transdisciplinary approach to pre-school program; Esperanza curriculum-Severe/Profound Integrated Activity System; strong family support systems (respite care; parent groups; counseling).

7.0 Agency's limitations/ areas requiring improvement Better coordination with other agencies need for more research.

Part B. Family Resource Services/Program

1.0 Program Abstract (Please include any formal literature about the Family Resource Services program.)

Description and Components of Family Resource Services Program

1.1 Historical Perspective (how, and when program was started) Program was begun in 1974 with HIP funds. It began with the intent of providing an alternative to institutionalizaing a child because there was no place to turn in an emergency situation, or for relief.

1.2 Where services are provided

A. In-home

B. Out-of-home agency respite facility (in residential neighborhood)

C. Institutional setting

D. Other

1.3 Means of delivery staff offer day and overnight short-term-out-of-home care

2.0 Population served through Family Resource Services (note: percentages may overlap)

2.1 Total number served daily overnight capacity is 6; can accomodate 4 more (total 10)

2.2 Age range 0-13 yrs. (we do make exceptions up to 18 years during day)

2.3 Disabilities of person served all developmental disabilities

2.4 Percentage age:

A. 0 - 5 44%

B. 5 - 18 56%

C. 19 - 29

D. 30 - 55

E. 55 and over

2.5 Percentage of severe/profound (multi-handicapped) 75%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? same as agency's - that of Janes Tauney

2.6 Persons who need intensive or specialized training/care 100%

Explain what is meant by those "who need intensive or specialized training/care" children needing to be fed; requiring medications and close observation for medical problems; lacking basic self care and communication skills; having poor impulse control.

2.7 Percentage non-ambulatory 27%

3.0 Recruitment of Family Resource Services Program staff

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3.1 Target group adults who have training and/or experience with D. D. children

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3.2 Method intra and inter agency contacts, local newspapers, UNM ads

3.3 Recruitment materials, tools used/developed media; university bulletin boards

4.0 Training of Family Resource Services

4.1 Target group Supervisors and assistants

4.2 Method agency inservice in cooperation with outside agencies, outside consultants, outside workshops

4.3 Curriculum Developmental disabilities; health needs and first aide; nutrition; positive feeding; behavior management; interaction techniques.

4.4 Training materials; tools used/ developed utilize "Life Project Group Home Parent Training" tapes

4.5 Source of funding agency

5.0 Community Development

5.1 Media resources Respite home slide/tape presentation; brochure; PSI; newspaper articles.

5.2 Parent education Pamphlets on prevention; communication of child's progress and techniques used by staff; informational letters and talks about respite care.

5.3 Agency education The same types of information are sent to other agencies serving developmentally disabled children.

5.4 Community education Use of media; speaking engagements before community groups

5.5 Materials; tools used/ developed slide/tape presentation; brochures

6.0 Administration

6.1 Criteria for eligibility of Family Resource Services Developmentally disabled children (0-13) who do not have extreme violent behavior or require skilled nursing care.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Minimum - 1 hr. Maximum - 3 months. Average monthly client utilization is 26 hours.

6.3 Methods of referral to program Schools, doctors, welfare department, probation officers; other service providers; parents, social workers through phone and written contacts.

6.4 Method of referral to service providers phone contacts, written referral

6.5 Cost of service to client/fees charged by agency/sliding scale see fee scales

6.6 Cost of service to agency (operating, indirect, capital costs) $1.28 per day

6.7 System of payment (broker, voucher, direct, to service provider, etc.)

6.8 Provisions for transportation Agency van available for field trips, doctor visits, etc; public schools provide school transportation.

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Board of Directors governs agency; Residential review committee develops policies and procedures. 203

7.2 State and local regulations, standards, guidelines, zoning State licensing regulations

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7.3 Current, pending, and future legislation _____

_____

8.0 Family Resource Services staff/personnel

8.1 Total number staff 6

8.2a Number supervisory staff/administrator 1

8.2b Professional expertise, special training or skills, relevant experience, etc. 5 yrs as special education teacher.

8.3a Number direct service staff 5

8.3b Professional expertise, special training or skills, relevant experience, etc. 3 have two or more years of college training; all have one or more years experience with handicapped children.

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) O.T. on a consultant basis

8.4b Professional expertise, special training or skills, relevant experience, etc. Registered O.T., training in sensory motor integration and child development.

8.5 Staffing patterns/system for scheduling direct services staff see attachment

_____

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc) began with H.I.P. funds; Title XX

B. State 25% match of Title XX money

C. Local County; OCETA

9.2 Client direct payment sliding fee scale- payments generate $300 monthly

9.3 Donations Money usually given for specific purposes (purchase of toys, etc.)

9.4 Other

10.0 Available Family Resource Services Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) doctors & nurses, teachers, parents, therapists, counselors, nutritionists, specialists in the field.

10.2 Agencies (supportive, ancillary, generic) Programs for children, ARC, Public Schools, Mental Health Mental Retardation Center, Los Lunas Training School and Hospital.

10.3 Materials/Tools Audio-visual presentations, workshops, literature, conferences

11.0 Needed Family Resource Services

11.1 Persons (parents, professionals, etc.) Parents, foster parents, teachers, social workers, doctors and nurses

11.2 Agencies (supportive, ancillary, generic) Public Schools, ARC, Programs for Children, Health and Social Services Department, Los Lunas Hospital and Training School

11.3 Materials/Tools

12.0 Strengths/strong points of Family Resource Services program Relief for parents and child, stimulating environment, consistent care, development of client skills, coordination with school and family.

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13.0 Identified weaknesses/limitations of Family Resource Services Lack of strong parent training component; no program during school hours; limited by number of spaces; age ranges, and level of care requirements - need to expand in all of these

14.0 Evaluation/Accountability

14.1 Internal Staff evaluations, agency evaluation, Residential Review Committee, parent evaluations

14.2 External J.C.A.H.

15.0 General Comments

16.0 Names and addresses of other programs and agencies providing this service that you are aware of and would recommend, etc.,

RESPITE AND GROUP HOME FEE SCHEDULE

January, 1978

If client's 24 hour charge equals...	0 hours up to 6 hours charge equals...	6 - 12 hours charge equals...	12 - 18 hours charge equals...
$2.30	$ .58	$1.15	$1.73
$2.71	$ .68	$1.35	$2.04
$3.12	$ .78	$1.56	$2.34
$3.53	$ .88	$1.77	$2.64
$3.94	$ .99	$1.97	$2.97
$4.35	$1.09	$2.18	$3.27
$4.76	$1.19	$2.38	$3.57
$5.17	$1.29	$2.59	$3.87
$5.59	$1.40	$2.80	$4.19
$5.92	$1.48	$2.96	$4.44

All charges must be paid within 90 days. Clients will be billed the 3rd week of every month.

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RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

FEBRUARY, 1978

Date: 4/24/78 Interviewer: Helen Smiddy, R.N.

Name of Agency: Division of Mental Retardation

Street: Route 1, Box 1000

City: Georgetown, State: Delaware Zip: 19947

Program Contact: Marianne Smith, R.N.

Title: Respite Coordinator Telephone: 934-9231; ext 9 or 90

Applied Definition for Respite: To provide a short term admission (up to three months during a calendar year) for implementing: 1. developmental program; i.e., self feeding or toileting; 2. behavioral management programs; i.e., decelerating a minor objectionable behavior; 3. relief to a family during illness or family crisis; and 4. vacation plans for the child and/or the family.

Part A: [illegible] Agency which is [illegible] Respite Program/Services

1.0 Population [illegible] by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) Entire State of Delaware

1.2 Total population agency [illegible], general populace; special segment) developmentally handicapped and/or mentally retarded

1.3 Age range of persons served no age limit--from birth on.

1.4 Disabilities of persons served [illegible], secondary and other) children and adults with developmental disabilities and/or diagnosed as being mentally retarded.

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped

50% - 60%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? We follow guidelines and definition of American Association of Mental Deficiency.

1.6 Percentage of those who require more than average (of popluation served) amount of training/care

What is the amount of staff time needed to provide this? enough staff to provide 24 hour supervision.

1.7 Percentage non-ambulatory 15 - 20%

2.0 Types of service offered through agency See attached flyer Respite in private homes; respite in the institution with on-going follow-up programming for infant stimulation, child health care, child development, behavioral redirection, and family education.

3.0 Sources of referral to agency parents; public and private agencies coming in contact with developmentally disabled; private physicians and Community Nursing and Developmental Program staff.

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Warren J. Gehrt, Acting Director and Joanna E. McCabe, R.N., Director of Nursing and Cottage Life

4.2 State and local regulations, guidelines, standards, zoning eligibility for institutional respite is in accordance with the preadmission committee of the HMR.

4.3 Current, pending, and future legislation none

5.0 Funding sources (percentage if known)

5.1 Federal X

5.2 State X

5.3 Local

5.4 Other X Private

6.0 Agency's strengths/areas of excellence (Explain/Describe) The simplicity of its administrative procedures allows for flexibility and creativity in meeting individualized needs of our clients and their families. Respite programs being supervised by Community Nursing and Developmental Program staff enhances continuity of services and informality.

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7.0 Agency's limitations/areas requiring improvement lack of sufficient funds to extend services.

Part B: Respite Program/Services

1.0 Program Abstract (Please include any formal literature about the respite program.) = See copy of Respite Procedure

Description and Components of Respite Program

1.1 Historical Perspective (how, and when program was started) Need for respite was identified by our present Director of Nursing and Cottage Life, Joanna E. McCabe, R.N. The respite program at HMR started 1971 and is coordinated by the Community Nursing and Developmental Program which works out of the Hospital for the Mentally Retarded. Beds were reserved in various living areas at HMR, which would most appropriately accommodate clients living at home.

1.2 Where services are provided

A. In-home X

B. Out-of-home X

C. Institutional setting X

D. Other X - community - residential

1.3 Means of delivery individualized

2.0 Population served through respite services (Note: percentages may overlap)

2.1 Total number served fiscal 1976 - 1977 served 170 clients

2.2 Age range no limit

2.3 Disabilities of person served all degrees of mental retardation

2.4 Percentage age:

A. 0 - 5 5% and increasing

B. 5 - 18 40%

C. 19 - 29 30%

D. 30 - 55 15%

E. 55 and over 10% and increasing

2.5 Percentage of severe/profound (multi-handicapped) 50%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? We follow guidelines and definitions of American Association of Mental Deficiency.

2.6 Persons who need intensive or specialized training/care 75%

Explain what is meant by those "who need intensive or specialized training/care" A developmental and/or behavioral program is instituted as needed and/or requested. Skilled Nursing Care: Example, tube feeding.

2.7 Percentage non-ambulatory 15 - 20%

3.0 Recruitment of Respite Program staff

3.1 Target group Institutional respite - staff already provided; private respite target group are experienced individuals from agencies dealing with the developmentally disabled.

218 3.2 Method Word of mouth recommendations and followed by investigation by Community Nursing and Developmental Program staff. 219

3.3 Recruitment materials, tools used/developed Word of mouth at the appropriate places.

4.0 Training of Respite Program staff

4.1 Target group Staff has had formal training and experience with the developmentally disabled through their previous agency of employment.

4.2 Method See 4.1

4.3 Curriculum See 4.1

4.4 Training materials; tools used/developed See 4.1

4.5 Source of funding See 4.1

5.0 Community Development

5.1 Media resources DARC Newsletter

5.2 Parent education Weekly parent groups and parent groups in conjunction with children's play group.

5.3 Agency education Continuing education through attendance at seminars, workshops, etc.

5.4 Community education Presentation of seminars, lectures by staff to public and private agencies. Participation on committees.

5.5 Materials; tools used/developed Community Nursing and Developmental Program brochure; appropriate slides, films and charts.

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6.0 Administration

6.1 Criteria for eligibility of respite services Clients who live in Delaware are eligible for the respite program if they have been dagnosed as mentally retarded. They may be of any age and have any degree of retardation below the hospital's criterion.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Length of stay may be from a weekend to four weeks. Any longer stay must be approved by the Pre-admission Committee at HMR. Clients may use the respite program as often as they wish up to three months a year depending upon the available respite beds. The average length of stay is 10-15 days, summer the most popular time.

6.3 Methods of referral to program telephone or direct contact with Community Nursing and Developmental Program staff

6.4 Method of referral to service providers telephone or direct contact.

6.5 Cost of service to client/fees charged by agency/sliding scale Private - $15/day ambulatory; $20/day non-ambulatory
Institutional - sliding scale

6.6 Cost of service to agency (operating, indirect, capital costs) $30.60/diem

6.7 System of payment (broker, voucher, direct, to service provider, etc.) private - direct

6.8 Provisions for transportation none (family's responsibility)

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees See organizational chart

7.2 State and local regulations (mandates, guidelines, zoning hiring of Community Nursing and Developmental Program staff done through Merit System Regulations.

7.3 Current, pending, and future legislation Pending legislation private respite funds will be available.

8.0 Respite staff/personnel

8.1 Total number staff 7

8.2a Number supervisory staff/administrator 2

8.2b Professional expertise, special training or skills, relevant experience, etc. Pediatric Nurse Clinical Specialist; child development counselor; behavioral therapist; knowledge of cause and prevention of mental retardation; genetics; counselling

8.3a Number direct service staff 5

8.3b Professional expertise, special training or skills, relevant experience, etc.

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) 11

8.4b Professional expertise, special training or skills, relevant experience, etc. public health nurse; Division of Social Service; Department of Public Instruction; Bureau of Visually Impaired; occupational therapy; physical therapy speech therapy; psychologist; music therapist; neurologist; Crippled Children's Service

8.5 Staffing patterns/system for scheduling direct services staff In accordance with institutional staffing

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc.) X

B. State X

C. Local

9.2 Client direct payment Yes - private respite home

9.3 Donations: none

9.4 Other:

10.0 Available Respite Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) Community Nursing and Developmental Program staff with physical therapist, behavioral therapist, music therapist, occupational therapist, psychologist; physician and public health nurse

10.2 Agencies (supportive, ancillary, generic) Department of Public Instruction; Delaware Association for Retarded Citizens

10.3 Materials/Tools Individualized written programs and equipment; pre and post respite summary as needed.

11.0 Need Respite Resources

11.1 Persons (parents, professionals, etc.) sitter or homemaker services

11.2 Agencies (supportive, ancillary, generic) expanding the services of Adult Activity Center; reliable transportation.

11.3 Materials/Tools

12.0 Strengths/strong points of Respite Program continuity of services by community based programs; decrease of regular awaiting admission list to HMR; maintenance of family unit.

13.0 Identified weaknesses/limitations of Respite Program expansion

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14.0 Evaluation/Accountability

14.1 Internal client records

14.2 External feed back from parents and community

CENTER FOR THE DEVELOPMENT
OF
COMMUNITY ALTERNATIVE SERVICE SYSTEMS

ROOM 4023 (BOX 118)
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(402) 541-7717

IN COOPERATION WITH:
MEYER CHILDRENS REHABILITATION INSTITUTE
THE UNIVERSITY OF NEBRASKA MEDICAL CENTER

November, 1977
(form edited January, 1978)

CONSUMER SURVEY

Numbers 1 and 2 may not apply to your present situation. However, the situation may have occurred in the past or you may anticipate it occurring in the future, if so, please respond as if the situations were happening in the present.

1.0 What do you do when you need to leave your son/daughter with someone?
I leave my son/daughter with/where
1.1 ___ relatives (immediate or extended family)
1.2 ___ neighbors or friends
1.3 ___ residential facility
1.4 ___ foster care home (board and care home
1.5 ___ sitters (if you check sitters, please indicate how sitter is paid)
Fee paid per hour by me $_____
Fee paid per hour by agency $_____
1.6 ___ other (please specify) _____

2.0 I have not left my son/daughter with anyone because:
2.1 ___ I have not found anyone willing to provide needed services.
2.2 ___ I have not felt the available persons were qualified.
2.3 ___ My son/daughter has too many problems.
2.4 ___ My husband/wife will not allow it.
2.5 ___ I cannot afford available services.
2.6 ___ other (please specify) _____

_____

3.0 Have you ever used any relief care or home support services available through local community agencies?
3.1 ___ yes
3.2 ___ no

4.0 In what kind of situation have you used these services?
4.1 ___ planned (e.g. for a vacation, weekend off, etc.)
4.2 ___ crisis or emergency
4.3 ___ both
4.4 ___ other (please specify) _____

5.0 If the following services were provided, please indicate how you would rate them. Please consider also past and future situations, for example:
(The following examples apply to those families who may not need a particular service now, but they could have used the service in the past or anticipate a need in the future.)

EXAMPLE of reason for need in the past: You may be the parent of a young adult. When your son/daughter was younger you needed in-home support training for emergency situations. Rate this service as if it were needed today.

EXAMPLE of reason for need in the future: You are the parent of a preschool child. In several years you think you will need a temporary living arrangement out-of-home for you son/daughter. Rate this service as if it were needed today.

	Needed	Not Needed	Uncertain/More Information Needed
5.1 Trained in-home support personnel to provide specific and specialized programs and/or training for my son/daughter.	___	___	___
5.2 In-home support training for parent (myself/spouse) and/or other family members.	___	___	___
5.3 In-home support personnel to provide sitter care for my son/daughter.	___	___	___
5.4 In-home support personnel to provide companionship for my son/daughter.	___	___	___
5.5 In-home support person to provide homemaker or home-health aide services.	___	___	___
5.6 In-home adaptive equipment or architectural barrier removal, modifications, etc.	___	___	___
5.7 Temporary out-of-home sitter care services (less than 24 hours).	___	___	___
5.8 Temporary out-of-home companionship for son/daughter.	___	___	___
5.9 Temporary out-of-home living arrangement and/or services (less than 14 days).	___	___	___
5.10 Temporary out-of-home living arrangement and/or services (15-30 days).	___	___	___
5.11 Self-help support group for parents and/or son/daughter (e.g. Pilot Parents, Association for Retarded Citizens, People First, United Cerebral Palsy, National Society for Autistic Children, Epilepsy Foundation of America, etc).	___	___	___
5.12 Family counseling (e.g. ministers, social worker, therapists, mental health clinics, etc.)	___	___	___
5.13 Medical/genetic counseling.	___	___	___

6.0 Would you use these relief care or home support services if they were provided?
6.1 ___ yes
6.2 ___ no

7.0 Considering only the services you checked in Number 5, indicate your ability to pay for them.

	Yes, Totally	Yes, To Some Degree	No
.1 In-home training for son/daughter.	___	___	___
.2 In-home training for parent(s).	___	___	___
.3 In-home sitter care.	___	___	___
.4 In-home companionship.	___	___	___
.5 Homemaker/home-health aide services.	___	___	___
.6 Adaptive equipment, architectural ba-riers.	___	___	___
.7 Out-of-home sitter care (less than 24 hours).	___	___	___
.8 Out-of-home companionship.	___	___	___
.9 Out-of-home living arrangements (less than 14 days).	___	___	___
.10 Out-of-home living arrangements (15-30 days).	___	___	___
.11 Self-help support group.	___	___	___
.12 Family counseling.	___	___	___
.13 Medical/genetic counseling.	___	___	___

8.0 How do you feel these services should be paid for? (Check all answers that apply)
8.1 ___ I should pay for this service.
8.2 ___ A public agency should pay.
8.3 ___ I should pay, with some help from a public agency
8.4 ___ other (please specify) _____

9.0 When would you be most likely to use/need respite services?

9.1 ___ evenings
9.2 ___ weekends
9.3 ___ weekdays
9.4 ___ holidays
9.5 ___ vacations
9.6 ___ summer
9.7 ___ other (please specify) _____

10.0 Approximately how many hours each day would you use/need these services?
10.1 ___ less than 4
10.2 ___ 4-9 hours
10.3 ___ more than 9

11.0 Approximately how many days each month would you use/need these services?
- 11.1 ___ less than one day
- 11.2 ___ 1-3 days consecutively
- 11.3 ___ 5-7 days consecutively
- 11.4 ___ 7-10 days consecutively
- 11.5 ___ 11-14 days consecutively
- 11.6 ___ more (please specify) _____

12.0 Check any of the following barriers you might encounter in obtaining the services you checked in Number 5. (Check all answers that apply).
- 12.1 ___ money
- 12.2 ___ family schedules
- 12.3 ___ transportation
- 12.4 ___ services needed are not available
- 12.5 ___ no information on services available
- 12.6 ___ lack of confidence in personnel providing services
- 12.7 ___ other (please specify) _____
- 12.8 ___ none

13.0 Son/daughter's:
- 13.1 ___ age
- 13.2 ___ sex

14.0 Does your son/daughter have a disability characterized as one of the following: (Check all answers that apply).
- 14.1 ___ mild mental retardation
- 14.2 ___ moderate mental retardation
- 14.3 ___ severe/profound mental retardation
- 14.4 ___ epilepsy
- 14.5 ___ cerebral palsy/orthopedic
- 14.6 ___ autism
- 14.7 ___ emotional disturbance or other behavioral problem
- 14.8 ___ learning disability
- 14.9 ___ other physical or neurological impairments
- 14.10 ___ non-verbal
- 14.11 ___ non-ambulatory
- 14.12 ___ visually impaired
- 14.13 ___ hearing impaired
- 14.14 ___ medically at-risk
- 14.15 ___ other (please specify) _____

15.0 My son/daughter currently resides:
- 15.1 ___ with parents
- 15.2 ___ with relatives
- 15.3 ___ alternative living program or foster home
- 15.4 ___ group home
- 15.5 ___ facility for intensive care/training
- 15.6 ___ nursing home
- 15.7 ___ institution (e.g. state hospital, state developmental center, etc.)
- 15.8 ___ other (please specify) _____

16.0 Please indicate your relationship to son/daughter:
- 16.1 ___ mother
- 16.2 ___ father
- 16.3 ___ guardian
- 16.4 ___ other (please specify) _____

17.0 Please check your age category:
- 17.1 ___ 15-19
- 17.2 ___ 20-25
- 17.3 ___ 26-35
- 17.4 ___ 36-46
- 17.5 ___ 46-55
- 17.6 ___ 56-65
- 17.7 ___ 66 and over

18.0 Please check the level of education you have completed:

You	Spouse
18.1 ___ grade school	18.1 ___ grade school
18.2 ___ some high school	18.2 ___ some high school
18.3 ___ high school graduate	18.3 ___ high school graduate
18.4 ___ some college	18.4 ___ some college
18.5 ___ college graduate	18.5 ___ college graduate
18.6 ___ vocational/technical/business school	18.6 ___ vocational/technical/business school
18.7 ___ M.A. or equivalent level	18.7 ___ M.A. or equivalent level
18.8 ___ education beyond Master's level	18.8 ___ education beyond Master's level
18.9 ___ other (please specify) _____	18.9 ___ other (please specify)_____

5

19.0 Which sentence best describes your present family situation:

19.1 ___ Both parents living in the home.
19.2 ___ Both parents caring for the son/daughter, but maintaining separate homes.
19.3 ___ Single parent with sole responsibility for caring for the son/daughter.
19.4 ___ Single parent but receiving help from friends, neighbors, or relatives in caring for son/daughter.
19.5 ___ Child not primarily living in the home.

20.0 Please indicate the ages of other children or dependents living in your home.

_____ _____ _____ _____ _____

_____ _____ _____ _____ _____

_____ _____ _____ _____ _____

21.0 What is the size of the community you live in?

21.1 ___ Rural (under 10,000)
21.2 ___ Town (10,000 - 50,000)
21.3 ___ City (50,000 - 250,000)
21.4 ___ Urban (250,000 and more)
21.5 ___ less than 50,000 but near larger urban area

22.0 What is the yearly income of your family before taxes?

22.1 ___ $0 - 4,000
22.2 ___ $4,000 - 8,000
22.3 ___ $8,000 - 12,000
22.4 ___ $12,000 - 16,000
22.5 ___ $16,000 - 20,000
22.6 ___ $20,000 and over

23.0 According to the Department of Labor, the median income for a family of four in 1975 was approximately $14,000. Based on this information and any special considerations in your household, how would you rate your income status?

23.1 ___ low income
23.2 ___ low-middle income
23.3 ___ medium-middle income
23.4 ___ high-middle income
23.5 ___ high income

24.0 Does your son/daughter qualify for or receive any public assistance?

24.1 ___ yes
24.2 ___ no

25.0 Does anyone else in your household receive:

25.1 ___Supplemental Security Income(SSI)
25.2 ___Aid to Families with Dependent Children (ADC)
25.3 ___Social Security
25.4 ___ other public assistance (please specify)

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NATIONAL RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT
(DHEW-#54-P-71176/07-02)

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CASS-4	Free of Charge	OVERVIEW PACKET FOR THE FIRST NATIONAL CONFERENCE ON TEMPORARY FAMILY SUPPORT SYSTEMS FOR DEVELOPMENTALLY DISABLED PERSONS; Agenda, Workshop Presenters, Evaluation Forms, Core components of Model Community-based Respite Service Systems of Temporary Relief Supports; National Advisory Committee and Resource Network.
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CASS-7B	$1.60	HOME SERVICES ASSOCIATION OF ST. PAUL, MINNESOTA. Homemaker Services for Developmentally Disabled Mothers, contains program description of St. Paul, Minnesota program and guidelines for setting up a program for developmentally disabled mothers. (32pp.)
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